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## Caregivers' Experiences Raising a Child with Fetal Alcohol Spectrum Disorder

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Graduate Program in Education

A thesis submitted in partial fulfillment of the requirements for the degree in Master of Arts

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CAREGIVERS' EXPERIENCES RAISING A CHILD WITH  
FETAL ALCOHOL SPECTRUM DISORDER

by

Aamena Kapasi

Graduate Program in Counselling Psychology

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Master of Arts

The School of Graduate and Postdoctoral Studies  
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## **Abstract**

The purpose of this study was to identify challenges and strengths of caregivers to a child with Fetal Alcohol Spectrum Disorder (FASD). Thirty-two caregivers raising a child with FASD participated in phone interviews that included the questions: "What challenges do you face in making your household function well?" and "What strengths do you have to make your household function well?" Responses to the questions were sorted by participants and the data was analyzed using multi-dimensional scaling and cluster analysis. In response to the question about challenges, seven concepts emerged: 1) Extra Responsibility on Caregivers, 2) Difficulty Keeping Daily Routine, 3) Lacking Professional and Personal Support, 4) Feeling Stigmatized and Isolated, 5) Managing Child's Self Regulation Problems, 6) Working with Child's Diminished Executive Functioning and 7) Addressing Child's Antisocial Behaviour. Four concepts emerged from the question about strengths, including: 1) Change Parenting Strategy for Different Children, 2) Use Non-Verbal, Sensory and Physical Strategies, 3) Stay Patient and Understanding and 4) Locate and Maintain External Supports. The concepts were compared and contrasted with the available literature.

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## **Chapter 1: Introduction**

Prenatal alcohol exposure causes Fetal Alcohol Spectrum Disorder (FASD), a pervasive neurological disorder that contributes to a wide range of disabilities. The effects of alcohol on the central nervous system cause physical, developmental, cognitive and behavioural abnormalities. The spectrum of FASD in Canada includes Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS) and Alcohol-Related Neurodevelopmental Disorder (ARND) (Chudley et al., 2005).

The present study explores caregivers' experiences of raising a child with FASD, with the goal of providing an understanding of effective parenting strategies and risk areas. Prior qualitative studies (Gardner, 2000; Granitsas, 2004; Michaud & Templem, 2013; Salmon, 2008; Sanders & Buck, 2010) have characterized a range of experiences of caregivers raising children with FASD. However none of these studies have focused on household daily functioning, nor attended to the specific strengths of caregivers. The study adds to the voices of caregivers in the literature who share expertise they possess about families' strengths with professionals that work with alcohol-affected children and their families. By learning what caregivers do to help, effective strategies can be identified and shared. As well, by learning more about the areas of need, attention and resources can be more appropriately placed.

### **Frequency of FASD in Canada**

FASD is the leading preventable cause of birth defects and developmental delays in Canadian children (Koren, Nulman, Chudley, & Looock, 2003). The prevalence rate of FASD is approximately 9 per 1,000 live births in the general population and FAS specifically has a prevalence rate of approximately 3 to 5 per 1,000 births (Sampson et

al., 1997; Public Health Agency of Canada, 2003). Prevalence estimates are known to be elevated in certain populations, such as those in the foster care system (Lange, Shield, Rehm, & Popova, 2013), in some Aboriginal communities (Werk, Cui, & Tough, 2013) and in the youth criminal justice system (Fast & Conroy, 2009; Zadunayski, Hicks, Gibbard, & Godlovitch, 2006). A Canadian study estimated the number of children in care with FASD by province, and Ontario was found to have between 612 and 2,096 children 18 and under with FASD in care with associated costs ranging from over 9 million to over 33 million (Popova, Lange, Burd, & Rehm, 2014). The Children's Aid Society of London and Middlesex found that 63.9% workers reported having children in their caseload they suspected have FASD (The Children's Aid Society of London and Middlesex, 2013).

However, due to the difficulty of diagnosis and the lack of knowledge about FASD in the population, studies attempting to find prevalence rates of FASD are thought to result in underestimates of the actual rates (May et al., 2006). Indeed, the majority of Canadians who are affected by prenatal alcohol exposure are misdiagnosed or not diagnosed and lack needed supports (Koren, Fantus, & Nulman, 2010). Ontario specifically, is lacking in resources, programs and services compared to other parts of Canada (Naumann, Reynolds, McColl, & Smith, 2013). A lack of coordination between health, education, social service and justice systems, as well as the different professions involved in diagnosis and management of FASD has contributed to problems getting services to those who need them most.

### **The Importance of Caregivers**

According to Streissguth (1997), a good home environment is the most important



protective factor for children living with FASD. A stable and nurturing home decreased the risk of developing secondary disabilities, such as mental health concerns, drug and alcohol use, disrupted school experiences and criminal activity two to four times (Streissguth et al., 2004). In addition, Jacobson et al. (2004) conducted a longitudinal study on seven-year-old children with FASD and found that an enriched home environment was associated with less severe effects in cognitive functioning. This finding suggested that home environment also buffered some cognitive deficits associated with FASD. The relationship between children with FASD and their caregivers is also a significant determinant of cost. Those with positive support had lower overall costs of care (Stade et al., 2009).

Compared to other families of children with disabilities, caregivers of children with FASD have distinctive struggles. From a qualitative study of mother's experiences raising a child with FASD, a theme that emerged was "everything we learned as parents does not apply when caring for a child with FASD" (Michaud & Temple, 2013), emphasizing the difficulty in learning to parent children with FASD. Moreover, the negative stigma against parents of children with FASD is a unique struggle this population faces. In a study of mothers in New Zealand, all mothers reported feeling responsible and most expressed feeling blamed by others (Salmon, 2008). Caregivers also must work to restructure their understanding of misbehaviour, seeing it for its neurological basis not a result of poor parenting or trouble making by the child (Bertrand, 2009).

### **Utility of Findings**

Families raising children with FASD need care, support and advocacy from

informed service providers and those who make funding decisions. Professionals working in the mental health profession, as well as those responsible for policy development may benefit from findings of the study.

Learning more about the home environment of children with FASD will enable psychologists, counsellors, social workers and other professionals in the mental health field to gain an understanding of the methods caregivers have found to interact in helpful ways with children who have FASD. Counselling may help parents – birth, adoptive and foster – work through their feelings surrounding the stigma that comes with having an alcohol-affected child, and also help to increase their mental well-being. Families of children with FASD may enter counselling for a wide range of reasons and will often need support to parent their affected children.

When working with affected children and their families, counsellors may need to re-frame their approach. Much of therapy works from the assumption that individuals have capacity to change as a result of consequences. Children and youth who are alcohol-affected however, typically do not have that ability and parents often change their styles and adapt their environment to suit the needs of the child. For example, coaching parents to use methods such as re-direction and removing stimuli can be very helpful.

In addition, counsellors and other mental health professionals can provide psycho-education about the effects of teratogens on the brain and unpredictable developmental pathways resulting in unique profiles of strengths and deficits in children and youth. They also need to help caregivers understand that they are not alone and be aware of community support groups for caregivers to attend. Counsellors must explain that caregivers need to be their child's advocate, likely for the rest of their child's life.

This research can potentially be used to inform policy makers regarding allocation of funding for developmental disabilities at home and in school. Children with FASD do not necessarily score below an intelligence threshold that activates funding for developmental disability. It is crucial to aid families in financially supporting children who are alcohol-affected given how important the home environment is for future success. Specialized treatment expenses, respite care and special learning needs add up costs for these families. Additionally, because of the need for constant supervision, parents may not be able to work enough hours to cover costs. In addition, children with FASD make up approximately 2-5% of school-aged children, however there is a lack of recognition in the education system regarding FASD.

### **Summary**

Birth, foster and adoptive parents raising a child with FASD know their children best and are well positioned to inform professionals how best to help. FASD is a complex disorder, requiring understanding from professionals, community and government. There is a gap in the literature exploring caregivers' household functioning and particularly focusing on the strengths they have. This research study highlights the challenges and strengths of caregivers raising a child with FASD.

## **Chapter 2: Literature Review**

In this chapter a review of the relevant literature including a brief history of Fetal Alcohol Spectrum Disorder (FASD), diagnostic criteria for FASD, causes and effects, as well as findings from a thematic analysis of the caregiving literature is presented.

### **Fetal Alcohol Syndrome**

In 1726, a report by the Royal College of Physicians to the British Parliament stated, "Parental drinking is a cause of weak, feeble, and distempered children." The effect of prenatal exposure to alcohol has been known for centuries, however only in the last century has the topic become prominent in research. Documented studies of alcohol-affected children began at the beginning of the 20th century, when Sullivan found that pregnancies of "drunkard" woman in prison in Liverpool had unusually high infant mortality rates. He noted that these findings had no hereditary aspect, but instead were a result of maternal drinking (Sullivan, 1899). In France, Ladrague (1901) reported high levels of miscarriage, "underdeveloped children", epilepsy and "idiocy" among children of alcoholic mothers. Years later, French physicians Lemoine, Harousseau, Borteryu, and Menuet (1968, as cited in Streissguth, 1997) reported characteristics of 127 children born to alcoholic mothers. They noticed these children had growth deficiencies, physical abnormalities, including particular facial characteristics and agitated, irritable characters. Worldwide attention to alcohol use and child abnormalities was demanded by American physicians a few years later when they published an article in the international medical journal, *Lancet*, documenting common physical features and behaviour in eight children of alcoholic mothers (Jones & Smith, 1973). Since this publication, the effects of prenatal alcohol exposure have been undisputed and literature on Fetal Alcohol Spectrum

Disorder has grown worldwide.

**Causes.** Despite recent efforts to educate pregnant woman on the risks of drinking while pregnant, approximately 2% of pregnant woman engaged in risky levels of drinking (Morbidity and Mortality Weekly Report, 2009) and 10.5% engaged in some level drinking while pregnant (Public Health Agency of Canada, 2008). Alcohol is a teratogen, meaning it is a substance that disrupts typical prenatal development. Ethanol crosses the placenta easily, so when the mother is drinking, the child is drinking the same amount (Riley & Vorhees, 1986). Some families were initially in denial when a child was suspected of having FASD. They pointed out other potential causes of the abnormalities such as complicated labour and delivery, early sickness or family breakup because it was difficult to accept that a child had FASD (Streissguth, 1997).

No amount of alcohol is completely safe to drink during pregnancy (Goodlett & West, 1992, as cited in Streissguth, 1997, pp.61). Binge drinking was found to be more harmful than casual drinking (Jacobson et al., 2004) and drinking was especially harmful in the first three weeks of gestation, during the development of the central nervous system (Polygenis et al., 1998; Konovalov, Kovetsky, Bobryshev, & Ashwell, 1997). Drinking throughout pregnancy was found to have more severe neuropsychological effects than exposure in only the first trimester (Korkman, Autti-ramo, Koivulehto, & Grabstrom, 1998). Older maternal age (Bagheri, Burd, Martsolf, & Klung, 1998), genetic factors (Chudley, 2009, as cited in Coons, 2013), nutrition (May & Gossage, 2011) and alcohol metabolism (Warren et al., 2001) each play a role as well.

**Diagnosis.** Fetal Alcohol Spectrum Disorder is an umbrella term for a range of disorders caused by prenatal drinking (American Academy of Pediatrics, 2000).

According to the Canadian guidelines for diagnosis, Fetal Alcohol Syndrome (FAS) is diagnosed with evidence of growth impairment, three facial abnormalities, evidence of impairment in the central nervous system and confirmed (or unconfirmed) maternal alcohol exposure. For partial Fetal Alcohol Syndrome (pFAS), diagnosis requires two facial abnormalities, evidence of impairment in the central nervous system and confirmed maternal alcohol exposure. Alcohol-Related Neurodevelopmental Disorder (ARND) includes confirmed maternal alcohol exposure as well as evidence of central nervous system dysfunction (Chudley et al., 2005) such as facial features, small head and body size, or sensorimotor dysfunction (Olson & Montague, 2011). It should be noted that different guidelines for FASD diagnosis have been used in different countries, and the Canadian guidelines omitted the diagnosis of Alcohol-Related Birth Defects which was present in other systems (Chudley et al., 2005).

**Effects.** FASD creates structural and functional brain damage leading to a wide variety of deficits (Streissguth, 1997). Primary effects refer to the direct impairments of the brain due to prenatal alcohol exposure. These effects include sensory processing difficulties (Jirikowic, Olson & Astley, 2012), working memory impairment (Rasmussen, 2005), language and communicative difficulty (Coggins, Timler, Olswang, 2007), visual motor problems (Korkman et al., 1998) and physical abnormalities (Olson and Montague, 2011). Executive functioning is often impaired, displayed by difficulty in logic (Aragon et al., 2008) and attention (Korkman et al. 1998). Other effects of poor executive functioning include problems with judgement, decision-making, difficulty with change and impulsivity (Malbin, 2004). Secondary effects occur in reaction to these primary deficits. For example, executive functioning impairments lead to poor planning and

organizing (Malbin, 2004). In addition, children often have difficulty recognizing emotions thereby contributing to a lack of social skills (Siklos, 2008).

In school, a child affected by prenatal alcohol exposure may present with low cognitive skills and often math difficulties (Coles, Taddeo, & Millians, 2011). Deficits in school are not due to low intelligence. Indeed, researchers have found average IQ scores in children affected by FASD (Rasmussen, 2005). Subtest profiles and scatter are more useful indicators of a child's strengths and difficulties.

### **Caregivers' Experiences**

A search on caregivers' experiences raising a child with Fetal Alcohol Spectrum Disorder was performed. Databases in health, education and social sciences (MEDLINE, ERIC and PsycINFO) were used. From the reference lists of articles located through the search, other sources were located. Several factors emerged from the literature on caregiver challenges and strengths.

### **Challenges**

It is potentially very difficult to make a household function well with an alcohol-affected child. Main challenges caregivers faced included environmental stresses, the hidden nature of alcohol-related disabilities and a lack of services.

**Environmental stresses.** Many factors in the family and home environment can add to the harmful effects of FASD on children and youth. Poor environmental factors, the need for constant care and difficulty transitioning into adulthood create challenges for caregivers trying to maintain a well-functioning household.

***Other postnatal environmental issues.*** In a longitudinal study of resilience of children with disabilities, children with FASD born to mothers who struggled with

alcohol use were found to be the least resilient (Werner, 1986). This was attributed to the difficulty that in addition to prenatal alcohol exposure, children also coped with the postnatal environmental effects of parental substance abuse. Olson et al. (2007) found that 85% of alcohol affected children ranging from birth to eight years of age had other prenatal exposures to substances and 83% had a postnatal environmental adversity level of either "some" or "high". Drugs and alcohol were often used as a coping mechanism, and in a study of birth mothers by Astley, Bailey, Talbot and Claren (2000) all 80 had addictions to alcohol that resulted from a history of emotional, physical or sexual abuse. Living with an alcoholic parent, being subject to abuse, or living in poverty were detrimental to a child with FASD and exacerbated the effects (Streissguth, Bookstein, Barr, Sampson, O'Malley, & Young, 2004).

Youth have disclosed that when birth families were struggling with life challenges, including addictions and health problems, they experienced emotional pain from the lack of solid and supportive relationships with their biological family even if they were in care (Burnside & Fuchs, 2013). In one study of alcohol-affected adolescents and young adults, 69% of birth mothers were deceased (Streissguth, Aase, Clarren, Randels, LaDue, & Smith, 1991). While Aronson (1984) noted that children living in foster or adoptive homes had fewer psychosocial symptoms (e.g. aggressiveness, drug abuse, insecurity) in relation to those living in biological homes, if the child was removed after six months of age the protective effect was modest. Addictions treatment, as appropriate, for birth families was essential to keep them together and support a positive environment for alcohol-affected children to grow up in (Olson & Montague, 2011).

***Constant supervision and stress.*** A high level of supervision is essential in



creating a safe environment for children with FASD (Kalberg & Buckley, 2007).

Assessed by the Scales of Independent Behaviour-R, 48% of children with FASD needed the second or third highest levels of support (intensive or frequent, respectively), whereas no typically developing children required this level (Jirikowic, Kartin, & Olson, 2008).

Caregivers have described the increased difficulty in allowing their alcohol-affected children more freedom as adolescents while still supporting them and keeping them safe (Michaud & Temple, 2013).

Community meetings in the United States addressed primary service needs for caregivers and one basic need mentioned routinely was respite care (Ryan, Bonnett, & Gass, 2006). Caregivers were in need of a break and respite care was difficult to find. In a comparison of parenting stress with Autism Spectrum Disorder, FASD caregivers were significantly more stressed and rated higher on a pessimism subscale (Watson, Coons, & Hayes, 2013). "Making time for themselves" was also a concept in a study Brown and Bednar (2004) reported as a challenge for caregivers of children with FASD.

***Transitioning to adulthood.*** Adolescents with FASD did not necessarily mature mentally, emotionally or socially as much as they did physiologically. Alcohol-affected youth typically functioned at a younger level than non-alcohol-affected youth (DeJoseph, 2011). Parents needed to plan for the long-term future when raising a child with FASD, and understand the possibility that they would need to remain very involved in their children's lives (Olson, Oti, Gelo, & Beck, 2009). Most individuals with FASD needed to live at home for the remainder of his/her lives or was likely to need supportive living arrangements to be successful.

Streissguth, Barr, Korgan, & Bookstein (1996) worked with 90 alcohol-affected

adults (average age 28 years) and administered a Life History Interview to their caregivers. It was found that half of the affected adults were working at the time of study and half of those had a job for longer than 12 months. Of the 90 adults, over half had problems obtaining or retaining a job. Almost all needed help with money management, and over three-quarters needed support to make important decisions because of "poor judgement" and "poor organizational skills". Furthermore, about two-thirds required assistance to obtain medical care and social services.

Services to integrate FASD affected youth and adults into the community were found lacking in a study conducted from British Columbia, with only about one quarter of participants having received support (Clark, Minnes, Lutke, & Ouellette-Kuntz, 2008). Caregivers were often left solely responsible for integrating their children and youth into the community, leaving those without a strong family support at a major disadvantage. Also, the heavy reliance on caregivers, who were not guided or supported in the process of community integration, created more burden and stress for them.

Families with an alcohol-affected child displayed less hope for the future than those with a child with Autism Spectrum Disorder. Families of children with Autism were hopeful about the possibility of marriage, employment and independence, whereas families of children with FASD lacked hope for their children in these areas and instead identified potential adversity in forms of illegal behaviour or unplanned pregnancy. Researchers speculated that the difference in levels of hope was due to differences in awareness of the disorder and available supports in the community (Watson, Hayes, Radford-Paz, & Coons, 2013).

**Hidden Disabilities.** FASD is a neurological disorder with impairments that have

few or no physical markers. Families relied on behaviours as indications of impairment. Behaviour problems occurred, and when not managed well, developed into secondary disabilities.

***Impairment cannot be seen physically.*** Since FASD is a hidden disability, it needs to be discovered, unlike many other physical disabilities where supports can be put in place immediately. The difficulty of identifying FASD and obtaining diagnosis meant many people affected with FASD did not know they had a neurological impairment, causing frustration to both themselves and their caregivers (Streissguth, 1997).

Caregivers needed to learn how to understand the needs of their child through his/her behaviours (Streissguth, 1997). Streissguth et al. (1991) reported that the faces of 61 youth and adults with FASD were less distinctive after puberty. Specifically those with ARND were at a disadvantage because of a lack of facial features. Although their neurological impairment was severe, the physical markers associated with FAS were not present for many youth, causing others to question the diagnosis (Streissguth & O'Malley, 2000; Rasmussen, 2005).

Children with FASD appeared higher functioning than they were because particular strengths masked difficulties. Pseudo-sophistication was common among children with FASD who appeared to understand more than they did. This was particularly evident in social skills, as children with FASD were very friendly, loving and charming (Malbin, 2004). When schools assessed for learning disabilities in children who were socially and academically struggling, FASD was often misdiagnosed as ADHD or conduct disorder, which stopped any further assessment and comprehensive planning (Brown, O'Malley, & Streissguth, 2011). Children were put on medication, which had

little effect on their central nervous system dysfunction.

***Managing difficult behaviours.*** Children with FASD were easily overwhelmed, and as a result, unpredictable and problematic behaviours occurred. Difficulties with emotional regulation and oversensitivity made high stimulus environments particularly difficult for alcohol-affected children to function well in (Olson & Montague, 2011). Deficits in self-regulation have been noted and the root is a neurological disability in controlling emotion (Brown, O'Malley, & Streissguth, 2011).

Once children with FASD were frustrated, they also had difficulty calming themselves down (Olson & Montague, 2011). Helping a child maintain emotional control was useful, as often children with FASD had high impulsivity and low response inhibition (Streissguth, 1997). Parents have been encouraged to learn triggers to tantrums to try to avoid them. However, once a tantrum occurred it was best to let it run its course, as long as the child was in a safe place (Child and Youth Working Group, 2007).

Additionally, in young children, Wengel, Hanlon-Dearman, and Fjeldsted (2011) found sleep disruption to occur far more often among children with FASD than controls. Sleep disturbances resulted from sensory processing difficulties common in FASD affected children. Challenging behaviours were caused or at least exacerbated by lack of sleep.

Children with FASD displayed tantrums, belligerence or aggressive behaviour and parents expressed that dealing with these issues and living in a chaotic environment affected their relationships as well as their own mental health (Phung, Wallace, Alexander, & Phung, 2011). Paley, O'Connor, Frankel, and Marquardt (2006) found that biological and adoptive parents of children with FASD had increased stress levels when

children demonstrated impaired functioning, behaviour problems and when the family had fewer resources. They did not find any difference in parenting stress and the child's severity of diagnosis. Internalizing problems, such as anxiety or depression, and externalizing behaviour problems, including disruptive and overactive behaviours, each independently and significantly contributed to parent stress. Internalizing and externalizing concerns caused parents to worry and were difficult to manage.

***Development of secondary disabilities.*** In a study of secondary disabilities, 415 caregivers of people with FASD were interviewed and Streissguth et al. (1996) found high prevalence rates of negative life situations in youth and adults with FASD. These experiences included inappropriate sexual activity, trouble with the law, disrupted school experience and drug and alcohol use. Over 60% of individuals with FASD were in trouble with the law at some point in their lives (Center for Disease Control and Prevention 1996, as cited in Kelly, 2011). Mental health problems were found in over 90% of the individuals with depression prevalent in adults and attention difficulty prevalent in children (Streissguth et al., 1996).

***Lack of Services.*** Across Canada there has been a lack of services for FASD. Funding barriers, lack of available and accessible services, as well as adequate and appropriate services have challenged FASD affected individuals as well as their families.

***Funding barriers.*** The annual cost to families for a person living with FASD was estimated to be over \$21,000 (Stade et al., 2009). Income was identified as a major challenge for parents raising children with FASD (Caley, Winkelman, & Mariano, 2009). Costs included medicine (Oesterheld, et al., 1998), respite care (Doig, McLennan, & Urichuk, 2008) and home schooling (Ryan, Bonnett, & Gass, 2006). Brown, Sigvaldason,

and Bednar (2005) found that foster parents of alcohol-affected children required additional support. Those who did not receive enough financial support to foster a child with FASD considered ending the placement (Brown, Bednar, & Sigvaldason, 2007).

***Availability and accessibility.*** In an environmental scan of services for eastern Ontario, researchers found a lack of available and accessible services. Long distances between services, waitlists and limited access based on eligibility criteria were common for those seeking an FASD diagnosis (Naumann et al., 2013). Often the services and clinics families needed were located in urban communities, and difficult for those outside to access (Brown, 2004).

However, even within urban areas, it was difficult for families to find a doctor comfortable in diagnosing FASD. Physicians were hesitant because of the stigma, shame and labelling associated with FASD. Many pediatricians felt like they were not prepared to diagnose FASD. In one study half of pediatricians felt prepared to diagnose FASD and about one-third were confident they could manage treatment (Gahagan, et al., 2006). Additional training from a dysmorphologist or other specialized medical professional helped physicians feel more comfortable making a diagnosis (Jones, Robinson, & Bakhireva, 2009).

Streissguth (1997) recommended a multidisciplinary team to diagnose FASD. This included a psychologist, occupational therapist, physical therapist, teacher, speech-language pathologist and social worker, and was a complex and time consuming process (Astley, 2011). Once the diagnosis was made, Olson and Montague (2011) note there was a high need for services to help families cope with the challenges faced raising a child with FASD, such as respite care, which was not easily acquired.

*Adequate and appropriate.* Caregivers needed support from knowledgeable community services, school staff and helping professionals to assist them in raising a child with FASD. Part of the challenge was the absence of early screening. Questions about prenatal drinking were not routinely asked in settings where they could easily have been, such as parenting and health care centers, and helping professionals were not typically trained to recognize potential physical or behavioural indications of FASD (Olson & Montague, 2011). If these questions and training became routine more children with FASD could obtain an early diagnosis.

Families needed to be willing to work with professionals (Weinberg, 1997), and professionals needed to be aware of both the expertise they themselves possess and what caregivers knew about what works (Olson & Montague, 2011). Professionals clearly benefitted families with their understanding of FASD, specifically symptoms and relevant interventions (Fast & Conry, 2009). However, there were limitations to some interventions. For example, medical professionals who knew that there were significant limits to effectiveness of medication with organic brain damage were able to be clear about the possibilities and adjunct treatments needed to address specific symptoms or challenging areas (Olson et al., 2007).

### **Strengths**

Areas identified as helpful for caregivers raising a child with FASD included education about the disorder, community support and creating a good home environment.

**Education about FASD.** Gaining education about FASD was important for all caregivers. Knowing about the disorder to obtain an early diagnosis, understanding the impairments of FASD and focusing on the child's specific deficits were beneficial for

helping caregivers keep their households functioning well.

***Early diagnosis.*** Receiving an early diagnosis greatly improved outcomes for a child with a FASD because informed caregivers began to access resources and supports early in their child's life (Streissguth, 1997). In particular, adoptive and foster parents were disadvantaged when a diagnosis was not given early because of the difficulty to obtain evidence of maternal alcohol use. These parents may have felt shame or blame for their child's behaviour, when in reality, the neurological impairments of the child had just not been discovered yet (Streissguth, 1997).

Early in infancy the brain created neurological pathways. If a diagnosis was early, parents could take advantage of neurological development and implement strategies to be neurologically reinforced (Olson & Montague, 2011). Unfortunately, many caregivers found it was difficult to get an early diagnosis. Indeed, few children were screened at birth for FASD, and during infancy, children with FASD appeared normal (Olson & Montague, 2011). It was not until behavioural problems arose later in childhood that parents began to wonder about neurological damage and the possibility of FASD (Streissguth et al., 1996).

***Understanding the impairments.*** Foster parents have indicated that lacking information about the child was a reason for problems in the family. For example, foster parents who did not know their foster child had FASD or lacked information about FASD struggled a great deal trying to understand the causes of behaviours they observed as well as ways to intervene (Brown et al., 2007). Caregivers benefitted from understanding the behavioural manifestations of the neurological impairments. Indeed, functional impairments were more related to stress in caregivers than the particular FASD diagnosis



(Paley et al., 2006).

When a caregiver understood the areas of the brain that were most damaged it was easier to empathize with the child and understand what needed to be done in order to help. Information about FASD helped parents understand their child's abilities and eased feelings of guilt from parents who may have blamed themselves for a child's misbehaviour (Weiner & Morse, 1994). Reframing caregivers' understanding of the child's behaviour as attributable to brain damage helped them form a more positive view of their child and they were more willing to change parenting style, motivated to parent and feel more effective (Olson & Montague, 2011).

Additionally, understanding the functional impairments of a child helped caregivers recognize their child's limitations and notice his/her strengths. For example, knowing the different stimuli that may trigger a tantrum or rage was vital to keep peace in the home (Streissguth, 1997). Caregivers also learned to work with discrepancy between the functional and chronological age of their child (Olson et al., 2009).

***Focusing on the child's specific deficits.*** The severity and range of effects that FASD presented were unique to each child. Matching strategic approaches to the individual child was vital because children with FASD were as heterogeneous as typically developed children. Streissguth wrote, "There is no universal intervention for individuals with FAS/FAE. There are only specific and unique solutions for the individual at hand. The better the individual's problem is understood by his or her advocate, the closer the two can work together and the more successful their efforts will be in identifying and addressing the problems and considering the resources and constraints at hand." (1997, pp. 166). Caregivers know their children best and were

therefore the best advocates (The Child and Youth Working Group, 2007).

**Community supports.** Raising a child with FASD was a lot of work and the presence of specialized supports was found to be necessary. Specialized support from friends and family, schools and educational bodies, as well as groups and professionals helped caregivers have a well-functioning household.

***Family and friendship support.*** Having a strong support system was a benefit for all families and especially those with an alcohol-affected child (Streissguth, 1997). A network consisting of immediate family and neighbourhood support was beneficial to foster parents (Brown, Sigvaldason, & Bednar, 2005). Respite care, within this network, was also essential (Parks & Novielli, 2000).

***School and educational support.*** Schools were highly influential in the lives of children with FASD and their families (Streissguth, 1997). Gorman (1995, as cited in Streissguth, 1997) interviewed students with FASD and noted that those who had not been expelled, suspended or decided to drop out of school reported having someone at school who cared about them, that they had a positive peer group and participated in extra-curricular activities. In the interest of locating evidence-based approaches for working with children with FASD, discussions were held with caregivers, teachers, administrators and professionals (Pei, Job, Poth, & Atkinson, 2013) resulting in three major priorities for success of children with FASD in school: 1) the need to focus on the whole child (physical, mental, emotional and social well-being), 2) a responsive assessment process (sensitive assessment and coordinated service response) and 3) building capacity in the school (knowledge among school staff about FASD in general, and plans for students in particular).

It has been found that teachers with different levels of experience and using specialized knowledge and equipment had different levels of success with children who had FASD. Experienced teachers were able to differentiate instructions for the affected child which was vital to his/her learning while beginner teachers, experienced frustration and were less likely to adapt their instructions (Ryan & Ferguson, 2006). Strategies such as minimal visual and auditory distractions in the classroom, high level of structure and clear, explicit instructions helped children be successful (Wilson, 2013). Computer games and interactive learning developed for special learning needs have also shown positive outcomes for alcohol-affected children (Kable, Coles, Taddeo, 2007; Coles, Strickland, Padgett, Bellmoff, 2007).

***Groups and professional support.*** Knowledgeable professionals, local clinics and FASD support groups helped families with children who have FASD. Parents and families with proper support do better in the long run (Bailey, 2007). Groups or one-on-one interactions with other parents helped relieve stress and allowed for sharing of information. Just knowing others who have gone through experiences of raising a child with FASD was helpful for caregivers. Parents with older children and youth were able to help prepare and support families of younger children with what to expect as the child aged (Olson & Montague, 2011).

***Home environment.*** Making the home environment as stable and consistent as possible with strong communication and caregivers who exhibited positive characteristics was essential to maintain a functioning household for a child with FASD.

***Consistency, stability and routine.*** Children with FASD benefited from calm, non-stimulating and highly structured environments. Repetition, stability and routine

were known methods to help a child with FASD function well in day-to-day life (Child and Youth Working Group, 2007). Stability and routine prevented overstimulation that occurred in response to unexpected change (Bertrand, 2009; Olson & Montague, 2011). It was important for the parent to change the home environment for the alcohol- affected child because it was unlikely the child would adapt to the home environment (Malbin, 2004; Olson & Montague, 2011).

***Strong communication.*** While some children learned by reasoning, alcohol-affected children needed to be taught explicitly. Streissguth (1997) highlighted that teaching alcohol-affected children what others learned by observation, such as how to be a friend and be socially appropriate, how to enjoy spending time alone and how to enjoy working at tasks were essential life skills that would help her or him. In general, children with FASD were very literal. They understood better when caregivers used short sentences and precise language (Lutke, 1993, as cited in Streissguth, 1997). The Child and Youth Working Group (2007) recommended communicating through eye contact, exaggerated paralinguistic behaviours and visual cues to help children comprehend what was expected. If exceptions to rules arose, caregivers would expect the child to experience confusion (Child and Youth Working Group, 2007).

***Positive caregiver attitudes and motives.*** The right kind of personality and skills in caregivers were found to bring out the best in children (Olson & Montague, 2011). Streissguth (1997) commented that sense of hope and a practical approach were important qualities for caregivers of children with FASD. Sense of competence and internal locus of control were also essential (Hassall et al., 2005). Additionally, flexibility, loving, high endurance and dedication have been reported as helpful caregiver

qualities (Brown, Sigvaldason, & Bednar, 2005).

Motives for fostering children with FASD have been explored. Researchers found prominent motivators to be witnessing positive change, helping the child focus on his/her strengths and assisting children with disabilities. Maintaining these motives was especially helpful for parents when stress was high. When parenting challenges were high stress was directly related to how positive the views of parenting were (Blacher & Baker, 2007).

### **Summary**

Fetal Alcohol Spectrum Disorder is a set of diagnostic categories that refer to disabilities associated with the effects of pre-natal alcohol exposure. This neurologically based disorder can compromise different levels of functioning. It is increasingly well understood and recognized in the research literature, however community awareness and services are in short supply. In order to provide affected children with the best care, it is essential that caregiver challenges and strengths be shared in order to provide families with knowledge and support to create a better home environment. Themes that emerged from a review of caregivers' strengths in the literature included positive influence of knowledge by caregivers and professionals about the disorder, good supports and a positive home environment. Negative influences identified in the FASD caregiving literature centered on environmental stresses, the "hidden" nature of disabilities and a lack of supports.

To buffer against the development of secondary disabilities, emphasis should be placed on a major influential factor: the home environment. Recognition of the expertise that families have to care for alcohol-affected children is essential. However, relatively

little is known about caregivers' experiences raising a child with FASD. Through interviews and analysis with caregivers directly, areas of strength and need are further explored in the present study.

### **Chapter 3: Methodology**

Research on parenting children who are alcohol-affected has utilized different methods with different informants to explore, describe and measure caregiving experiences. Studies have relied on caregivers or professionals to obtain information about alcohol-affected children. This was done because the focal questions required responses that children may not have the experience, knowledge or ability to answer (eg. Jirikowic et al., 2012; Streissguth et al., 2004; Wengel et al., 2011). Other studies used caregivers or professionals as participants because they wanted information from a caregiver or professional's perspective specifically (eg. Brown & Bednar, 2004; Pei et al., 2013). For either reason, when caregivers participate in research for FASD, they are indirectly benefiting their own child and family by advocating for more knowledge about FASD (National Institute of Mental Health, 2009).

Studies have used telephone interviews with open-ended questions to collect data (Clark et al., 2008; Streissguth et al., 2004). Open-ended questions allowed for "rich descriptions of the respondents reality" (Jackson & Trochim, 2002), and telephone collection offered a relatively low cost. Interviews increased the likelihood of accurate responses, as participants were able to respond as they felt appropriate and were able to ask for clarification as well as elaborate on responses (Appleton, 1995). Kerlinger (1986, as cited in Heppner, Wampold, & Kivlinghan, 2008) argued that interviews allowed for the potential to obtain depth of information.

The present study was based on semi-structured telephone interviews with caregivers in partnership with local organizations with an interest in FASD to explore caregivers' experiences raising a child or youth with either confirmed or suspected FASD.

## **Concept Mapping**

Concept mapping is a quantitative analysis of qualitative data (Trochim, 1989). This approach promotes structure and objectivity in qualitative research (Burke et al., 2005). It has been used to assess construct validity (Davis, 1989) and assist in program planning and evaluation (Trochim, 1989). Concept mapping has also been utilized in studies to explore a range of topics from different perspectives. For example, concept mapping has been used in research with foster parents on their needs and challenges (Brown et al., 2007), professionals on assessment methods in mental health with children (Fesmire, Lisner, Forrest, & Evans, 2003) and educators on ways to promote adaptive e-learning (Stoyanov & Kirschner, 2004).

A range of ideas is generated by a specified group of individuals in response to a focal question. These ideas are returned to participants who are asked to independently group them together into concepts. The groupings are analysed statistically to produce a visual representation of the main ideas as participants organized them. There are six steps in the process: preparation, generation, structuring, representation, interpretation and utilization.

## **Procedure**

**Preparation.** The study was conducted in collaboration with local community organizations with a focus on FASD. The organizations advertised the study to potential participants. Eligible participants were adults caring for a child or youth with diagnosed or suspected FASD willing to partake in a telephone interview. Interested individuals responded to advertisements by contacting the researcher directly. At the time of contact each was provided with a description of the study and, in accordance with the approved



university ethics protocol, provided verbal consent to participate. The present study focused on two questions: “What challenges do you face in making your household function well?” and “What strengths do you have to make your household function well?” (See Appendix for interview form).

*Neurobehavioral Screening Tool (NST)*. Because it has been difficult to obtain a diagnosis, many families were raising children and youth suspected of FASD. It was decided that because these families possessed important insight on caring for an alcohol-affected child they would be included in the present study. Children suspected of FASD were screened for participation using the NST.

Nash, Rovet, Greenbaum, Fantus, Nulman, & Koren (2006) developed the NST to aid people working with children suspected of FASD to support the suspicion via the child or youth's behaviour in the previous six months. Since diagnosis by physical features is often difficult to assess, and not all children with FASD exhibited them, Nash and colleagues (2006) looked to develop a behavioural phenotype of FASD.

The NST was created from ten items on the Child Behaviour Checklist that were predictive of a FASD diagnosis, and it was administered to knowledgeable caregivers. The NST was found to be more effective with older children (12-17 years old) than younger children (6-11 years old) (Nash et al., 2006). In the development of the measure, the NST had a strong sensitivity rate of 86% and a specificity rate of 82% compared to controls. In a study comparing children with FASD, children with confirmed prenatal alcohol exposure without an FASD diagnosis and a control group, 36% of children with FASD screened positively, compared to 14% of prenatal exposed children and 0% of controls. Although the sensitivity of the NST was found to be modest (only accounting

for 36% of FASD diagnosed children), the specificity rate was high with none of the controls screening positive (LaFrance, Nash, Koren, Andrew, & Rasmussen, 2006). The NST has two screening methods that can be used to create a positive screen and when using screen (a) the false positive and false negative rates are lower than 20% (Nash et al., 2006).

**Generation of Responses.** Caregivers were asked several open-ended questions including the focal questions for the present study. If the child had confirmed FASD, the specific diagnosis was obtained. If the child was suspected of FASD, the Neurobehavioural Screening Tool (Nash, Koren, & Rovet, 2009) was administered. The NST was administered 13 times and four interviews were excluded from the study based on a negative screen. The researcher scored the results of the screen after the interview was completed. The researcher took notes during the calls, and calls were audio-recorded, with participant consent, to ensure no information was missed. Each participant was also asked to provide an address for the gift card to be mailed. Participants were then asked about their interest in participating in the second phase of the study. If so, contact information was recorded.

A total of 32 caregivers participated in the study. The majority were female (84%) with five males participating (16%). On average the caregivers had raised 2 children with FASD and had been a caregiver for 10 years. An average number of total children in the household was between 2 and 3. The average age of the child with FASD was 12 years. The majority of the families had an income between \$50,000-100,000, and 90% of participants had another caregiver in the home.

**Structuring of the responses.** Two researchers independently reviewed all

responses made by question. If a response was identified as unclear or redundant by either researcher it was discussed by both and a decision was reached. In the case of a redundant response, it was removed for the purposes of analysis. If the response was considered unclear it was edited for clarity. There were 81 unique responses for the question: “What challenges do you face in making your household function well?”. There were 74 unique responses for the question: “What strengths do you have to make your household function well?” Participants interested in the second phase of the study were contacted by telephone. Each who was willing to participate in the sorting task was mailed out a complete set of responses. Each response was printed on a separate card. Participants were instructed to sort the cards, by question, in whatever way made sense to them. Fifteen sorts were returned to the researcher for each question.

**Representation of responses.** Sort data was entered into the Concept Systems (2014) which used non-metric multi-dimensional scaling and hierarchical cluster analysis to identify the underlying conceptual structure. A concept map was created for each question.

***Multi-dimensional scaling.*** Multi-dimensional scaling in concept mapping plotted all responses on a map (Kruskal & Wish, 1978). The first step in this analysis was to construct a similarity matrix. One matrix was created for each participant’s sort. Response ID numbers were arranged on the top and side and each time two responses were grouped together, the cell where they intersect was represented with a 1. All other cells were 0. The matrix for each participant was stacked and totals for all cells were calculated. The second step in this analysis was to represent the matrix in distances between the responses. A point map was created where distances between responses

represented the average frequency of each response sorted with each other response.

Multidimensional scaling also produced a bridging index value for each response. The bridging index was a value between 0 and 1, which referred to the frequency with which that response was grouped together by participants with other responses nearby on the point map. Responses with a high bridging index value (i.e. over 0.75) “bridged” (were often sorted by participants together) with responses not only nearby on the map but with responses in other areas of the map. Responses with a low bridging index value (i.e. under 0.25) rarely “bridged” (were rarely sorted by participants together) with responses in other areas of the map.

**Cluster analysis.** Multidimensional scaling results were used in the cluster analysis to organize responses into concepts (Anderberg, 1973; Everitt, 1980). At the beginning of this analysis each response was treated as its own cluster. At each step, two clusters were combined until at the end, all responses were in one cluster.

**Interpretation.** To decide on the optimal number of concepts for the map the researcher used qualitative and quantitative data. Maps with different numbers of concepts were reviewed and compared. The “best” map for a particular question was based on similarities between responses within each concept and differences between responses in different concepts (Kane & Trochim, 2007). The bridging value was also used. Average bridging indices were calculated for each concept and lower average indices (i.e. below 0.25) indicated greater consistency (i.e. responses in the concept were rarely grouped by participants with responses in other concepts). Higher average bridging indices (i.e. above 0.75) indicated less consistency (i.e. responses in the concept were often grouped by participants with responses in other concepts).

**Utilization.** A key feature of this method is that participants are directly involved in the analysis and application. Once created, the use of the map is limited only by the creativity and motivation of the users (Trochim, 1987). Participants can challenge the results and find ways to apply the findings into their own situations (Kane & Trochim, 2007). For the purposes of the present study the concept maps provided a basis to represent the perspectives of caregivers (presented in Chapter 4) to make comparisons with the existing literature on caregivers' experiences to identify any potential issues that have not already been identified in this important area of study (presented in Chapter 5).

## **Chapter 4: Results**

The purpose of the study was to identify challenges and strengths of caregivers to a child with Fetal Alcohol Spectrum Disorder (FASD). Telephone interviews were conducted with caregivers who later sorted all responses provided into groups. The sorting data was analyzed statistically and a concept map for each question was constructed based on the analyses. In this chapter, the results of the concept mapping analysis are presented for each question: “What challenges do you face in making your household function well?” and “What strengths do you have to make your household function well?”

### **Challenges**

A total of 81 unique responses were provided to the question: “What challenges do you face in making your household function well?” Fifteen participants sorted the responses. The sorted responses were analyzed using multidimensional scaling and cluster analysis. Validity is measured by a stress value. Maps with stress values below 0.35 are generally considered to be valid representations of the sort data (Trochim, 1989). A stress value of 0.27 was found for the present map.

To determine the most appropriate number of concepts for a map with fewer than 100 responses, solutions between 20 and 3 should be considered (Trochim, 1989). In each solution concepts were examined for evidence of within concept consistency of responses and discrepancy between concepts. Starting with the default 20-concept solution, there was clear fragmentation. A solution of ten concepts was considered. Changes introduced in the reduction to nine and eight concepts increased the differentiation between concepts, but the responses were still fragmented. The seven-concept model represented a

good fit with the data. The five and six concept maps were reviewed. However further reduction from seven concepts combined conceptually different content together and created over-generalized concepts. The solution that provided the best interpretability was the seven-concept map (see Figure 1). Responses and bridging indices are presented in Table 1.

Individual bridging indices were used to identify the most central responses within each concept (i.e. responses with the lowest individual bridging index were most central to the content of that particular concept) and provided guidance for labelling. Responses with a low bridging index, between 0.00 and 0.25, indicated that they had been frequently sorted only with the other responses within the concept. Responses with a high bridging index, between 0.75 and 1.00, had been frequently sorted by participants with responses in other concepts as well. High bridging did not conceptually fit only with the responses near to them on the map, and were less likely to reflect the overall content of a concept (Trochim, 1989). An average bridging index as calculated for each concept based on the individual bridging indices. The lower the average bridging index, the greater the frequency with which the responses in it were sorted only with other responses in the same concept.

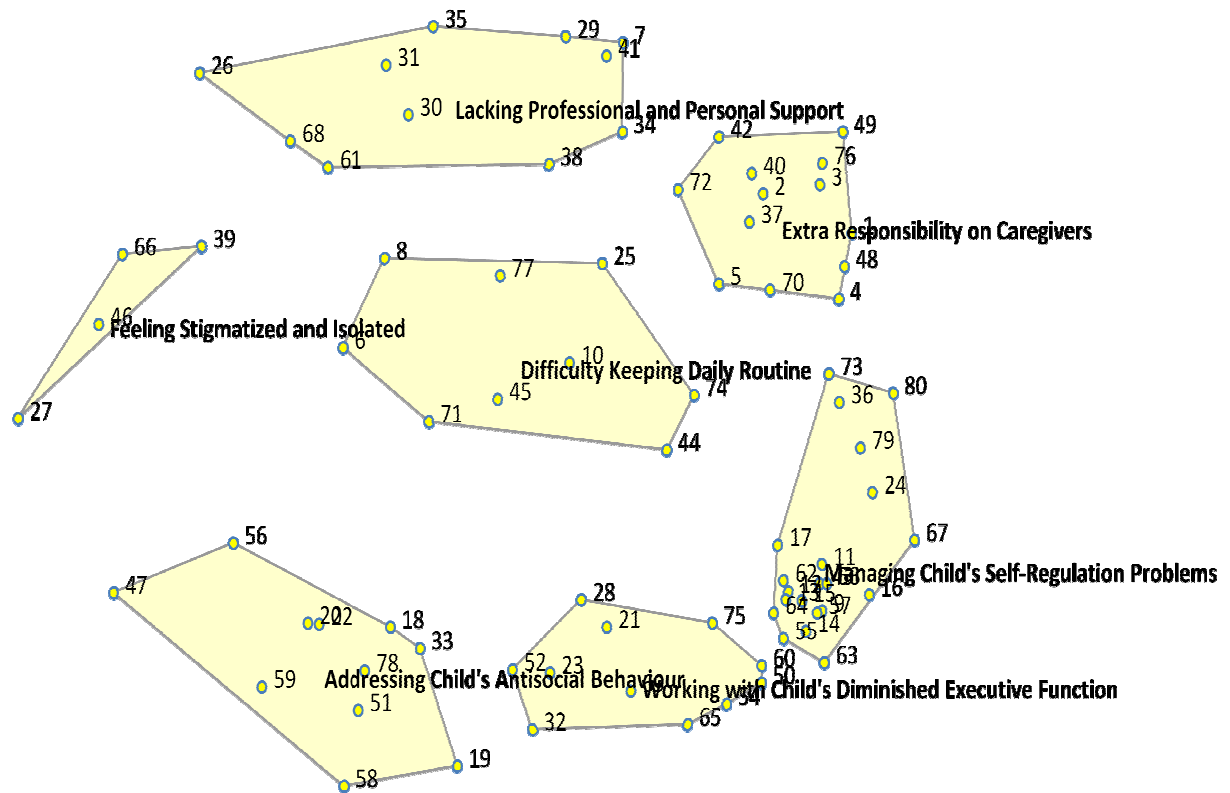


Figure 1. Concept Map: What challenges do you face in making your household function well?

Table 1

Responses and Bridging Values for Concept Map for Question One: Challenges

Concept and Response	Bridging Index
Extra Responsibility on Caregivers	0.31
70.Keeping things calm and consistent is challenging	0.22
5.Can't have regular sitters or leave him/her with anyone	0.25
4.Big time commitment	0.27
48.Having someone be there to be their external brain	0.29
37.FASD is not in the school system and there is no policy	0.29
2.Activities that have one on one support are difficult to find or very expensive	0.30
1.24/7 supervision	0.30
73.Need respite	0.30
40.Few services that deal with FASD specifically	0.32
3.Advocating with systems for supports he/she needs	0.36
77.Requires a lot of energy	0.36
42.Frustration seeing no results	0.39
49.Having to advocate	0.44



Difficulty Keeping Daily Routine	0.37
44.Hard to find his/her triggers	0.16
75.Need to promote good hygiene	0.18
10.Challenging to find a medication that works	0.29
25.Constantly having a schedule is challenging	0.31
45.Hard to find motivators as child has no want or need	0.36
78.Reschedule day to fit his/her state that day	0.39
71.Layer of attachment disorder due to adoption	0.45
8.CAS does not adequately prepare families	0.59
6.Can't make promises that you don't know will happen for sure	0.59
Lacking Professional and Personal Support	0.59
34.Family find it challenging to be around behaviours	0.38
38.Feel isolated and helpless	0.43
41.Financial challenges	0.48
7.Caregivers are chronically sleep deprived	0.50
29.Don't get time together with partner	0.54
30.Don't get to do family outings	0.60
68.Huge wait lists to see professionals and for programs	0.65
35.FAS fairly unknown/not recognized still	0.66
31.Don't know where to turn to get help	0.68
61.Need OT and PT services	0.75
26.Difficult to get diagnosis	0.78
Feeling Stigmatized and Isolated	0.79
39.Feel stigmatized	0.75
46.Have to drive to get into the city and get services	0.75
27.Difficult working with biological mother	0.83
66.Homeschooling means no breaks	0.85
Managing Child's Self-Regulation Problems	0.10
12.Child acts impulsively	0.00
13.Child can be volatile and over-react	0.01
62.He/she presents like they know what's going on, but don't	0.01
64.He/she triggers very easily	0.02
15.Child can't handle his/her emotions	0.02
9.Cause and effect concept is not there for him/her	0.02
14.Child can recite rules but won't remember in moment	0.03
11.Child acts about half their age	0.03
57.He/she is immature	0.04
43.Gets obsessed with things	0.05
55.He/she has poor executive functioning	0.05
53.He/she has memory deficits	0.06
17.Child has high sensory issues	0.07

63.He/she takes things literally	0.11
16.Child has difficulty understanding consequences	0.12
80.Transitions are very difficult	0.20
24.Constant re-direction	0.22
74.Need to keep realistic expectations of what he/she can do	0.24
36.FASD is a hidden disability	0.27
81.Trial and error process for everything	0.28
67.Huge discrepancies between emotional intelligence, intellectual, and physical ability	0.33
Working with Child's Diminished Executive Function	0.22
76.Rages, tantrums, and meltdowns	0.09
60.He/she lacks common sense	0.09
50.He/she can't understand the reason for rules	0.12
21.Child is very suggestible	0.18
54.He/she has no accountability	0.19
69.It is an effort for him/her to remember and sequence ex. morning routine	0.22
28.Difficulty with siblings ex. gets frustrated when playing games	0.23
23.Children often alienated in social situations	0.30
65.He/she has no concept of time	0.30
52.He/she has irregular sleep patterns	0.32
32.Eating is challenge	0.37
Addressing Child's Antisocial Behaviour	0.58
33.Extreme lying	0.39
18.Child hoards food	0.41
79.Stealing is a problem	0.45
22.Child wanders off	0.45
19.Child is always defiant	0.48
51.He/she has coordination concerns	0.55
20.Child is not able to do chores or help out	0.61
59.He/she is self abusive	0.66
56.He/she is frequently kicked out of school	0.66
58.He/she is physically under sensitive	0.70
47.Have to monitor TV and computer time as it is easily over stimulating	1.00

**Extra responsibility on caregivers.** This concept represented the extra onus that caregivers raising a child with FASD had compared to those raising typically developing

children. Responses such as "keeping things calm and consistent is challenging", "can't have regular sitters or leave him/her with anyone", "big time commitment", "having someone be there to be their external brain", "requires a lot of energy", and "24/7 supervision" reflected extra parenting responsibility as a constant challenge caregivers faced. In addition, "advocating with systems for supports he/she needs" and "having to advocate" emphasized the need for caregivers to campaign on behalf of their child, which was a very challenging task as many people in the community were not FASD aware or knowledgeable, and those with FASD were typically not able to advocate for themselves.

The responses "FASD is not in the school system and there is no policy", "activities that have one on one support are difficult to find or very expensive", "need respite" and "few services that deal with FASD specifically" demonstrated the challenges of finding community services. These responses had a bridging index above 0.29 and were therefore not as central to this concept, but did speak to the extra responsibility placed on caregivers due to lack of community support. These responses may have also been sorted with responses in the concept of Lacking Professional and Personal Support. Additionally, the response "frustrating seeing no results" implied the challenge caregivers had in seeing positive change in their child. Its bridging value was also relatively high to that of other responses within the concept which suggested that it may have also been grouped together with responses in other concepts.

The overall bridging value for this concept was at 0.31. This bridging value suggested that responses in this concept were not always sorted only with one another, but often together and in general represented a similar idea.

**Difficulty keeping daily routine.** Another challenge in making a household

function well was maintaining a stable routine. This was reflected in the responses "need to promote good hygiene", "reschedule day to fit his/her state that day", "challenging to find a medication that works" and "constantly having a schedule is challenging". The responses "hard to find his/her triggers", "can't make promises that you don't know will happen for sure" and "hard to find motivators as child has no want or need" reflected the difficulty caregivers had maintaining a routine.

"Layer of attachment disorder due to adoption" and "CAS does not adequately prepare families" both described the challenges faced by the adoptive and foster parents raising children with FASD. Both responses had high bridging indices (0.45 and 0.59, respectively), indicating that they were not consistently grouped with the other challenges pertaining to a daily routine. This concept had an average bridging index of 0.37, which suggested that some responses were sorted with responses in other concepts.

**Lacking professional and personal support.** A lack of professional support was represented in the responses "difficult to get diagnosis", "need OT and PT services", "don't know where to turn to get help", "huge waitlists to see professionals and for programs" and "financial challenges". A lack of personal support was demonstrated in the responses "family find it challenging to be around behaviours", "don't get time together with partner" and "don't get to do family outings". A general lack of support from friends, family and professionals was reflected in the responses "feel isolated and helpless", "caregivers are chronically sleep deprived" and "FAS fairly unknown/not recognized still". This concept had the second highest bridging index at 0.59 which indicated that participants often sorted responses in it with responses in other concepts.

**Feeling stigmatized and isolated.** Most central to this concept was the response

"feel stigmatized" and the next most central response was "have to drive into the city and get services". This concept represented stigmatization and isolation, which caregivers raising a child with FASD faced, especially those located in small communities who needed to drive into cities for services.

The response "difficult working with biological mother" described the challenge adoptive or foster parents had with communication and connection to their child's biological mother. With a 0.83 bridging index, this response was also often sorted with responses in other concepts. "Homeschooling means no breaks" was a challenge for caregivers who home schooled, since they were constantly with their child. This response also had a high bridging index (0.85), indicating that it too was frequently sorted with other responses in other concepts. This concept had the highest bridging index at 0.79, which indicated that responses within it were sorted with the responses in the other concepts. This concept may have reflected more than one main idea in addition to Feeling Stigmatized and Isolated.

**Managing child's self-regulation problems.** A number of responses reflected difficulty managing a child's poor self-regulation. This was reflected in the responses "child acts impulsively", "child can be volatile and over-react", "he/she triggers very easily", "child can't handle his/her emotions", "child acts about half their age", "he/she is immature", "gets obsessed with things", "child has difficulty understanding consequences", "child has high sensory issues", "transitions are very difficult" and "constant re-direction".

Several responses highlighted the challenges of being uncertain about progress of children with FASD. These responses included "he/she presents like they know what's

going on, but doesn't", "need to keep realistic expectations of what he/she can do" and "trial and error process for everything". The responses "cause and effect concept is not there for him/her", "he/she has poor executive functioning", "he/she takes things literally", "child can recite rules but won't remember in moment" and "he/she has memory deficits" all related to cognitive abilities. In addition, the responses "FASD is a hidden disability" and "huge discrepancies between emotional intelligence, intellectual, and physical ability" reflected the neurological nature of this disorder, where most problems could not be seen. This concept had the lowest bridging index at 0.10 which indicated that responses in it were consistently sorted together.

**Working with child's diminished executive function.** Caregivers identified challenges that indicated their child's executive functioning was compromised. The responses "he/she lacks common sense", "rages, tantrums, and meltdowns", "he/she can't understand the reason for rules", "child is very suggestible", "he/she has no accountability", "it is an effort for him/her to remember and sequence" and "he/she has no concept of time" outlined behavioural evidence of compromised executive functioning. The challenge caregivers experienced in working with low social skills was seen in the responses "difficulty with siblings eg. gets frustrated when playing games" and "children often alienated in social situations".

Having a consistent routine of sleeping and eating also presented a challenge to caregivers of children with FASD, demonstrated by the responses "he/she has irregular sleep patterns" and "eating is a challenge". These problems may have stemmed from an inability to use normal executive functioning, for example, transitions and planning. This concept had the second lowest bridging index at 0.22 which indicated that responses in it

were consistently sorted with each other.

**Addressing child's antisocial behaviour.** This concept contained a number of antisocial behaviours that caregivers saw in children with FASD including "extreme lying", "child hoards food", "child is always defiant", "he/she is self abusive", "child wanders off" and "he/she is frequently kicked out of school". "Child is not able to do chores or help out" implied functional daily living challenges. The other responses related to neurological difficulties alcohol-affected children had including "he/she has coordination concerns" and "he/she is physically under sensitive". Finally, the response "have to monitor TV and computer time as it is easily over-stimulating" had a bridging index of 1.00, and was as often grouped with responses in other concepts as it was with responses in this concept. Overall, this concept had a bridging index of 0.58 which indicated a moderate level of inconsistent sorting with responses inside and outside the concept.

### **Strengths**

A total of 74 unique responses were provided to the question: "What strengths do you have to make your household function well?" Fifteen participants sorted the responses. The sorted responses were analyzed using multidimensional scaling and cluster analysis. The stress value is a validity measure. Maps with stress values below 0.35 are generally considered to be valid representations of the sort data (Trochim, 1989). A stress value of 0.27 was found for the present map.

To determine the most appropriate number of concepts for a map with fewer than 100 responses, solutions between 20 and 3 should be considered (Trochim, 1989). In each solution concepts were examined for evidence of within concept consistency of responses

and discrepancy between concepts. A visual examination of a map with the default 20 concepts indicated a great amount of scatter and no conceptual picture. Solutions with ten, nine and eight concepts were still too fragmented. A solution of six came closer, with some fragmentation, but smaller numbers of concepts were still more likely to reflect underlying structure. Reducing the map even further to five concepts combined two similar concepts. When reduced to four, two very similar concepts merged, and when combined, created a consistent idea. Further reduction to three concepts lost significant detail, thus the four-concept solution was determined to be most appropriate for this question (see Figure 2 for concept map). Responses and bridging indices are presented in Table 2.

Individual bridging indices were used to identify the most central responses within each concept (i.e. responses with the lowest individual bridging index were most central to the content of that particular concept) and provided guidance for labelling. Responses with a low bridging index, between 0.00 and 0.25, indicated that they had been frequently sorted only with the other responses within the concept. Responses with a high bridging index, between 0.75 and 1.00, had been frequently sorted by participants with responses in other concepts as well. High bridging did not conceptually fit only with the responses near to them on the map, and were less likely to reflect the overall content of a concept (Trochim, 1989). An average bridging index as calculated for each concept based on the individual bridging indices. The lower the average bridging index, the greater the frequency with which the responses in it were sorted only with other responses in the same concept.



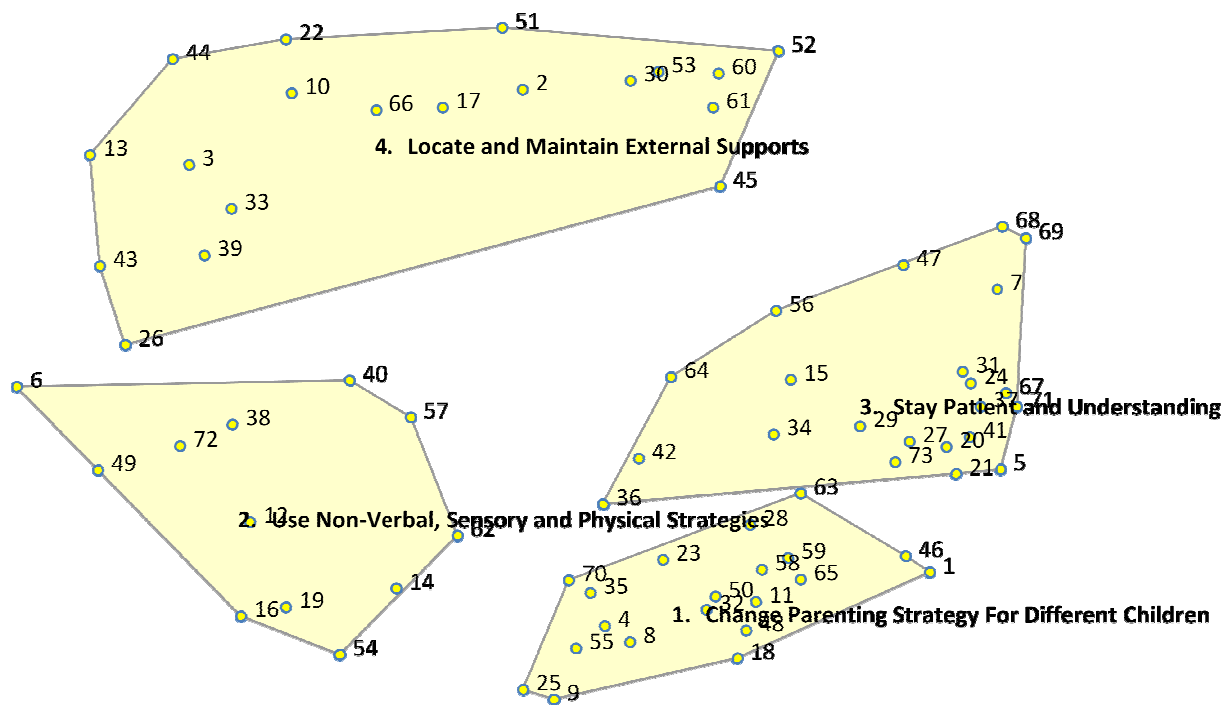


Figure 2. Concept Map: What strengths do you have to make your household function well?

Table 2

Responses and Bridging Values for Concept Map for Question Two: Strengths

Concept and Response	Bridging Index
Change Parenting Strategy for Different Children	0.12
16.Distract by talking about something else he/she would be interested in	0.00
46.Modifying expectations	0.02
24.Give him/her a choice, which gives him/her the control	0.03
9.Catch rages before full blown	0.03
15.Direct to things that make use of his/her strengths	0.04
63.Slow and calm talking to give him/her time to process	0.06
51.Nothing to over-stimulate him/her (eg. few decorations, limited furniture, few guests)	0.07
42.Lots of warnings before transitions	0.07
11.Children need reassurance	0.09
70. Use concrete terms and language-be literal	0.11
56.Re-focus away from what is upsetting them	0.11
39.Keep home a calm, low key, and structured environment	0.11
26.Go past behaviour into what the issue is	0.12

4.Always have a household routine-predictability	0.13
28.Maintain good communication about what is happening when child is upset	0.16
66. Teaching him/her boundaries	0.17
19.Ease into situations to avoid over-stimulation	0.17
73.Walking away from fits and tantrums	0.20
65. Teach same skills in different environments to get them familiar with transferring skills	0.28
49.Need to plan ahead	0.42
Use Non-Verbal, Sensory, and Physical Strategies	0.58
12.Communicate non-verbally	0.28
60.Sensory things work well (eg. weighted blankets, brushing, body sock)	0.38
17.Doing physical activity outside helps a lot	0.39
55.Picture and visual cues	0.47
34.Get involved in extra-curricular activities	0.53
20. Exaggerated emotions helps child recognize them	0.53
36.Headphones and iPad for music, books, and games	0.56
58.Rewards system has been fairly helpful	0.64
25.Give him/her cue cards as reminders	0.68
62.Set boundaries and know your own limits	0.74
68. Timer help with morning and night routines	0.80
2.Accept the lifestyle and embrace it	1.00
Stay Patient and Understanding	0.20
54.Patience	0.08
1.Ability to advocate	0.08
47.Monitor own reactions and not react negatively to child	0.09
40.Know that the behaviour is not intentional	0.10
45.Making effort to find ways that work through trial and error	0.11
53.Optimistically as possible, but realistically as possible	0.12
37.High tolerance and understanding	0.13
38.Keep him/her on a sleep schedule is important	0.14
33.Accept that it isn't fixable	0.15
43.Love him/her	0.16
32.Whisper instead of yelling	0.16
69. Use a lot of humor	0.16
59. See the effort, not achievement	0.17
10.Children have taught us so much	0.17
7.Being very supportive and validating	0.18
3.Adaptive and versatile	0.20
50.Not be afraid of conflict	0.21
18.Don't rely on the system, know it's on us	0.27
67.Teamwork as a family	0.39

27.Get as much knowledge as possible	0.40
5.Being able to work as a team with your partner	0.47
6.Being home and having time for your child	0.53
Locate and Maintain External Supports	0.56
52.Once I got diagnosis, supports were easier	0.39
61.Service dog works really well	0.44
29.Lots of parenting experience makes it easier	0.47
44.Made connections with adults living with FASD	0.50
23.Financial stability	0.50
13.Connecting with specialized professionals (ex. OT,PT, SLP)	0.50
72.Use Facebook as a communication outlet	0.51
21.We are valued in community	0.52
64.Subsidized day care for social development	0.52
57.Respite worker helps a lot	0.53
14.Peer support	0.54
35.Medication helps him/her be less reactive	0.56
71.Use cultural methods including spiritual strengths, traditional medicines	0.58
8.Careful about which other kids are coming into foster home	0.61
22.Family and friends are understanding	0.61
48.Music helps a lot	0.61
31.Have a card that tells people triggers	0.67
41.Lock everything up and put alarms on their doors	0.67
30.Good pediatrician giving lots of information	0.84

**Change parenting strategy for different children.** This concept represented strategies caregivers made to best parent the unique needs of their children. They talked about the importance of understanding their children, as well as using behavioural strategies to prevent problems as well as manage problems after they arose. Caregivers noted that they also had to "modify expectations" of their children and "need to plan ahead" so that they could "teach same skills in different environments to get them familiar with transferring skills". They also found it was important to think about patterns and their own child to understand what is going on inside for her or him. The response "go past behaviour into what the issue is", reflected the need to put themselves in their

child's frame of reference.

Caregivers noted that they would "keep home a calm, low key, and structured environment" so as to provide "nothing to over stimulate him/her". They also talked about the importance to "always have a household routine-predictability", "give him/her a choice, which gives him/her the control", "use concrete terms and language-be literal" as well as provide "lots of warnings before transitions". Other preventive approaches were "maintain good communication about what is happening when child is upset", "slow and calm talking to give him/her time to process". It was very important, according to caregivers, that the "children need reassurance" and that they spent time "teaching him/her boundaries".

In response to challenging situations, caregivers found that it was helpful to "re-focus away from what is upsetting them" and "direct to things that make use of his/her strengths" or "distract by talking about something else he/she would be interested in" in order to "ease into situations to avoid over-stimulation" and "catch rages before full blown". They also found that it was important to find ways, when the child was safe, for them to be "walking away from fits and tantrums". In terms of bridging index, the concept attained the lowest average bridging index (0.12) indicating that responses within it were consistently sorted together with each other and not with responses in other concepts.

**Use non-verbal, sensory and physical strategies.** Responses in this concept referred to the importance of finding a range of ways to interact with their children for support and sharing information to arrive at mutual understanding. Participants talked about the need to "communicate non-verbally" with their children as well as "sensory

things work well" as did the use of "picture and visual cues". They described the need to sometimes use "exaggerated emotions helps child recognize them". Additionally, the noted that memory difficulties could be improved by "give him/her cue cards as reminders" or "timer help with morning and night routines" and that "rewards system has been fairly helpful". They talked about equipment that could help control the environment they were in such as "headphones and iPad for music, books, and games". It was also important for the children to be involved in "normal" activities that promoted communication with peers outside of home, such as "doing physical activity outside helps a lot" and having them "get involved in extra-curricular activities".

There were responses that referred more broadly to the kinds of attitudes and activities that helped them feel balanced as caregivers so that they could remain creative and adaptive for finding ways to communicate with their children. For example, "accept the lifestyle and embrace it" and "set boundaries and know your limits" showed strengths that caregivers used to maintain a positive mental state. Overall, this concept had the highest bridging index at 0.58, indicating that responses in this concept were sorted with responses in other concepts.

**Stay patient and understanding.** The responses in this concept referred to the importance of caregivers remaining balanced in their dealings with their children and family but fiercely loyal and expressive about the special needs the children had to be met in order for them to have a fair chance of inclusion in the school and community. Keeping patient was reflected in several responses including "patience", "monitor own reactions and not react negatively", and "make effort to find ways the work through trial and error". Additionally, understanding was reflected in the responses "know that the

behaviour is not intentional", "optimistically as possible, but realistically as possible", "high tolerance and understanding", "accept that it isn't fixable", "see the effort, not the achievement", "being supportive and validating", "adaptive and versatile" and "get as much knowledge as possible". They also talked about the importance of "being home and having time for your child" and the rewards of parenting were evident in the response "children have taught us so much".

Other responses in this concept reflected strategies caregivers used to help their children outside of home. The responses "being able to work as a team with your partner" "teamwork as a family", as well as "love him/her" and "keep him/her on a sleep schedule is important" were necessary prerequisites for themselves and their children, respectively, to stay effective in their dealings with others. In addition, caregivers talked about the importance of the "ability to advocate" and "not be afraid of conflict" but to "use a lot of humor" as needed and to even "whisper instead of yelling" when dealing with others. They had to work hard on making it possible for their children to have a full life outside of home because they "don't rely on the system, know it's on us" for their care. This concept had a bridging index of 0.20, signifying consistent sorting of responses within it with each other and not with responses in other concepts.

**Locate and maintain external supports.** This concept included responses that reflected the importance of external support. This support included both mainstream and traditional Indigenous approaches. In addition to the "use cultural methods including spiritual strengths, traditional medicines", participants also described the need to have a "good paediatrician giving lots of information". In addition, although some support was available to anyone, such as feeling like "we are valued in community" and to "use

Facebook as a communication outlet", other supports were more specialized such as "subsidized day care for social development", and still others were specific to FASD such as "connecting with specialized professionals" and "made connections with adults living with FASD".

Major prerequisites to having access to external services were associated with "financial stability" and "once I got a diagnosis, supports were easier". These two factors paved the way for additional access. Resources such as a "service dog works really well" and "respite worker helps a lot" were allocated on the basis of being a client of a system and the diagnosis of FASD. In addition, the specialized medical care led to opportunities for "medication helps him/her be less reactive" and networking, leading to "peer support" and with increased confidence, having "family and friends are understanding".

Caregivers noted that "lots of parenting experience makes it easier" to care for an alcohol-affected child. With experience, as well as confidence and support, both formal and informal, caregivers were more confident to share what worked for them with others. Some responses reflected tools and techniques that caregivers found strengthened their household functioning, such as "music helps a lot", "have a card that tells people triggers", "careful about which other kids are coming into foster homes, and "lock everything up and put alarms on their doors". A bridging index of 0.56 was found for this concept which indicated that some responses were sorts with responses in other concepts.

## **Results Summary**

Fifteen caregivers raising a child with FASD sorted 81 responses to the question, "What challenges do you face in making your household function well?". The sorting data was analyzed using multidimensional scaling and cluster analysis to reveal seven

concepts: 1) Extra Responsibility on Caregivers, 2) Difficulty Keeping Daily Routine, 3) Lacking Professional and Personal Support, 4) Feeling Stigmatized and Isolated, 5) Working with Child's Diminished Executive Functioning, 6) Managing Child's Self-Regulation Problems and 7) Addressing Child's Antisocial Behaviour.

Extra Responsibility on Caregivers included responses indicating increased levels of responsibility when parenting a child with FASD, such as "keeping things calm and consistent is challenging, and "24/7 supervision". Difficulty Keeping Daily Routine represented the challenge caregivers had keeping a daily routine, shown in responses "reschedule day to fit his/her state that day", challenging to find a medication that works" and "need to promote good hygiene". Lacking Professional and Personal Support was represented by responses such as "family find it challenging to be around behaviours", and "huge waitlists to see professionals and for programs", signifying a lack of professional and personal support. Another challenge for caregivers was shown in Feeling Stigmatized and Isolated through responses "feel stigmatized" and "have to drive into the city and get services". Working with Child's Diminished Executive Functioning contained responses reflecting poor self-regulation, demonstrated by "child acts impulsively" and "child can be volatile and over-react". Responses in Managing Child's Self-Regulation Problems such as "he/she lacks common sense", "he/she can't understand the reason for rules" and "it is an effort for him/her to remember and sequence" all demonstrated challenges for managing neurological impairments. Finally, Addressing Child's Antisocial Behaviour included antisocial responses such as "extreme lying" and "stealing is a problem", which showed that a challenge caregivers faced was the problematic behaviours of children.



The second question: "What strengths do you have to make your household function well?" included 74 unique responses sorted by 15 caregivers raising children with FASD. Following analysis, responses were organized into four concepts: 1) Change Parenting Strategy for Different Children, 2) Use Non-Verbal, Sensory and Physical Strategies, 3) Stay Patient and Understanding and 4) Locate and Maintain External Supports. Examples of responses in Change Parenting Strategy for Different Children were "modifying expectations" and "direct to things that make use of his/her strengths", which reflected the need to change parenting strategies for children with FASD to have a functioning household. Use Non-Verbal, Sensory and Physical Strategies warranted the use of non-verbal, sensory and physical strategies to strengthen household functioning, as evident in responses such "communicate non-verbally" and sensory things work well". Stay Patient and Understanding focused on the caregivers themselves, and the importance of "patience" and understanding, as shown by "know that the behaviour is not intentional". Locate and Maintain External Supports emphasized the use of external supports by caregivers, such as "we are valued in the community" and "connecting with specialized professionals".

## Chapter 5: Discussion

The purpose of the study was to identify challenges and strengths of caregivers to a child with Fetal Alcohol Spectrum Disorder (FASD). Participants were asked two focal questions: “What challenges do you face in making your household function well?” and “What strengths do you have to make your household function well?”. Responses were collected from 32 caregivers by telephone interview and 15 caregivers who participated in the interviews sorted the responses into groups. The sort data was analyzed with multidimensional scaling and cluster analysis using the Concept System (2014). In this chapter the results of the study are compared to the existing literature.

### Challenges

The question: "What challenges do you face in making your household function well?" resulted in a map with seven concepts. The concepts included: 1) Extra Responsibility on Caregivers, 2) Difficulty Keeping Daily Routine, 3) Lacking Professional and Personal Support, 4) Feeling Stigmatized and Isolated, 5) Working with Child's Diminished Executive Functioning, 6) Managing Child's Self-Regulation Problems and 7) Addressing Child's Antisocial Behaviour. There was a great deal of overlap between the responses provided by participants in the present study with what has been reported in the literature. However, some differences were found.

**Extra responsibility on caregivers.** Caregivers described the challenge of having additional responsibilities than would be required for children with other special needs or those without special needs to make their household function well. The literature was partially consistent with the responses in this concept.

Jirikowic et al. (2008) found that 48% of children with FASD required high levels

of support while no typically developed children needed this level of support. Kalberg and Buckley (2007) noted that a high level of supervision was crucial for children with FASD to keep them safe. Caregivers in a study by Brown and Bednar (2004) reported that a challenge for caregivers raising a child with FASD was "making time for themselves" including reference to time and energy required and lack of FASD informed babysitters and extra-curricular programs. In addition, respite care was a need for caregivers in a study by Parks & Novielli (2000). Caregivers in the present study also reported this need.

Lack of FASD awareness in schools and the need to advocate for children with FASD was evident in this concept and also in the literature. Children with FASD have struggled in school both academically and socially (Cole et al., 2011; Siklos, 2008). Lack of FASD sensitivity can create a difficult relationship between parents and the school. The responsibility for their child's education regularly falls on the caregivers (Streissguth, 1997).

Caregivers in the present study expressed frustration as a result of seeing no results from their efforts. This challenge has not been noted in previous literature. It is possible that caregivers have tried different techniques and had difficulty finding something that worked for their child. This response was novel to this study because previous literature has not placed much focus on household functioning or the mental well-being of caregivers.

**Difficulty keeping daily routine.** Although it has been documented that keeping a stable and routine household was important for children with FASD (Strissguth et al., 2004), caregivers in the present study found it very difficult to actually achieve this. This

challenge has not been previously noted by caregivers in the literature.

Caregivers have learned triggers and motivators (Child and Youth Working Group, 2007) to maintain a functioning home environment, yet in the present study, they found this very difficult to predict and act on. Once a child is triggered, it may be impossible to carry on with the daily routine. Challenges for caregivers also arise in finding a medication that works, promoting good hygiene and not feeling prepared by Children's Aid Society.

It is known that children with FASD have difficulty with routine and adaptive functioning (Jirikowic et al., 2008; Malbin 2004). Children with FASD rated lower on an assessment of Independent Behaviour in the area of living skills than typically developed children (Jirikowic et al., 2008). However, the implications of these deficits for caregivers have not been thoroughly explored in the research.

Although not central to this concept as indicated by a high bridging index, working with CAS and attachment issues that come with adoption were evident in the literature. Foster and adoptive parents raising a child with FASD have unique challenges in making their household function well.

**Lacking professional and personal support.** This concept indicated that lack of support was a challenge. This has been noted in the previous literature. However some responses within this concept had not been previously reported.

Caregivers in the present study identified difficulties with family members and personal relationships. Personal supports were difficult to maintain as many caregivers' lives revolved around their children. Also, lack of information about FASD created misunderstanding and stigma in families and communities (Salmon, 2008; Sampson et

al.,1997). In addition, financial challenges were reported in this study, as well as in previous literature (Caley et al., 2009).

Finding professional support was extremely challenging for caregivers raising a child with FASD. This was consistent with literature which included a lack of professional services for the FASD population (Naumann et al., 2013). Diagnosis has been a continuing challenge for caregivers. A shortage of professional understanding about FASD combined with variable and indistinct diagnostic criteria as well as the large body of professionals needed to complete the assessment make access to diagnostic services very difficult for caregivers (Astley, 2011). If a diagnosis was obtained, there was then a need for follow up to help the family (Olson & Montague, 2011), however the services were not available. A study by Gahagan et al. (2006) found only 34% of pediatricians felt ready to manage treatment of FASD.

Challenges reported by participants in the present study but not evident in the literature include the feeling of being alone in their struggle. Caregivers in this study reported the challenges the family had when a member has FASD, including lack of family outings and no alone time with one's partner. These results may be novel to this study, as the existing research has not thoroughly investigated family functioning in families with an FASD-affected member.

**Feeling stigmatized and isolated.** In this concept, caregivers noted an emotional challenge faced in raising a child with FASD. Feeling stigmatized and isolated were consistent with previous literature. Salmon (2008) found that biological mothers felt blamed by others for their child's disorder. Anyone perceived as being a biological mother may feel this same stigmatization. Furthermore, caregivers, particularly those

outside of urban centers and the school system, were isolated from many professional services. A lack of services in rural communities has been reported previously. Brown (2004) noted that accessibility to services and clinics was difficult for those in rural or remote locations.

Of interest is the finding of the present study that homeschooling was done by participants. This has not been identified within the existing literature. Caregivers of children with FASD have to advocate for their children in the school system often because of a lack of general understanding as well as policy that includes FASD (Naumann et al., 2013). Caregivers in the present study, decided that homeschooling their child would provide a more responsive and effective learning environment and education. This effort requires caregivers to have personal strength, political will and financial stability.

**Managing child's self regulation problems.** This concept included responses surrounding challenges caregivers faced managing their child's poor self regulation, as well as attributions made about the causes of these problems. These challenges are consistent with the literature.

Caregivers have expressed that poor emotion control is characteristic of children with FASD (Brown, O'Malley & Streissguth, 2011). Children with FASD have difficulty calming themselves down once frustrated and sometimes these frustrations become tantrums and rages (Olson & Montague, 2011). It is likely that many frustrations experienced by children with FASD are due to their sensory processing difficulties (Jirikowic, Olson, & Astley, 2012), which was also noted in the responses of this concept. Lack of self control makes it easy for children with FASD to act impulsively

(Streissguth, 1997).

The invisibility of FASD was a response sorted into this concept which has been noted in the literature. Since it is not possible to see the neurological damage of alcohol exposure, parents may feel responsible for their child's misbehaviour and attribute it to bad parenting. Once they are aware of FASD, parents are forced to understand and interpret their children through behaviours (Streissguth, 1997). People were found to question the FASD diagnosis due to lack of facial features, even though the neurological deficits were severe (Rasmussen, 2005; Streissguth & O'Malley, 2000).

Children with FASD often function at a younger level intellectually, socially and behaviourally than typically developing children (DeJoseph, 2011). Many caregivers also identified this as a concern in managing their child's self-regulation difficulties.

Neurological impairments in children with FASD drastically change children's development and thus children with FASD do not function at their chronological age (Olson et al., 2009), which can be very distressing for caregivers, especially as children age and discrepancies widen.

Previous research has shown that belligerent or aggressive behaviour at home has impacted family relationships and the mental health of the family (Phung et al., 2011).

One study found that when children with FASD demonstrated behaviour problems or impaired functioning, parent stress levels increased and especially when the family had fewer resources (Paley et al., 2006).

**Working with child's diminished executive functioning.** Compromised executive functioning was evident in the responses that participants grouped together. In the literature, academics and professionals have reported on executive functioning.

However, caregivers are clearly noticing this cluster of symptoms and their interconnections with a common source. They were aware that there was neurological basis underlying behaviours, such as lacking common sense, poor logic, difficulty with cause and effect and struggles with time.

As an effect of the neurological damage in children with FASD, often executive functioning was affected. Executive functioning refers to several cognitive functions, including judgment, decision-making, difficulty with change and impulsivity (Malbin, 2004). Other areas of executive function are logical reasoning (Aragon et al., 2008), working memory (Rasmussen, 2005), and attention (Korkman et al., 1998). Malbin (2004) noted poor planning, organizing and schedule following among alcohol-affected children. The difficulties from problems in executive functioning noted by researchers overlap a great deal with those identified by caregivers.

Caregivers also reported children with FASD having irregular sleep patterns in this concept. Although this response had a high bridging index, which indicated that it was frequently sorted with other concepts, this challenge is consistent with research by Wengel et al. (2011), where it was reported that young children with FASD often have difficulty sleeping due to atypical sensory processing.

The problems associated with executive functioning according to caregivers have not been identified in the literature to this point. This finding suggested they had good recognition of behaviour and its relationship to brain function. Caregivers in this study were connected to a local clinic, caregiver or professional organization as well as other parents involved with these agencies and groups. The caregivers in this study were well informed about FASD. Many may have read literature, or gone to formal presentations or



trainings where executive functioning was discussed.

**Addressing child's antisocial behaviour.** This concept included responses that related to children's antisocial behaviour, creating a particular challenge for caregivers of children with FASD. Antisocial behaviour has been noted in the previous literature on FASD.

Watson et al. (2013) compared families with a child with FASD to those that have a child with other developmental disabilities and found that only children with FASD demonstrated illegal activity as part of the profile. Bertrand (2009) stressed that caregivers needed to restructure their understanding of antisocial behaviours, attributing them to neurological deficits, not poor parenting or trouble-making. Unfortunately, antisocial behaviours often lead to involvement with the justice system. Youth and adults with FASD are overrepresented in the justice system (Streissguth et al., 1996; Zadunayski et al., 2006).

Some responses in this concept suggested mental health concerns in children with FASD. This also has been seen in the literature. In one study, Streissguth et al. (1996) found 90% of youth and young adults with FASD had mental health problems. Self abusive behaviours and hoarding suggest maladaptive coping (McKay, Wood, & Brantley, 2007) and poor information processing (Steketee & Frost, 2003) which are known issues for people with FASD (Alberta Learning, 2004; Jirikowic et al, 2008).

### **Strengths**

The second question: "What strengths do you have to make your household function well?" resulted in a map with four concepts. The concepts included: 1) Change Parenting Strategy for Different Children, 2) Use Non-Verbal, Sensory and Physical

Strategies, 3) Stay Patient and Understanding and 4) Locate and Maintain External Supports. In general, these concepts overlapped a great deal with issues identified in the caregiving literature. However, some differences were apparent.

**Change parenting strategy for different children.** Caregivers responses indicated that they changed parenting strategies for children with FASD which helped make their households function well. Responses in this concept overlapped completely with the existing literature.

The concept included specific techniques that caregivers used to parent their alcohol-affected child. Michaud and Temple (2013) found the theme "everything we learned as parents does not apply when caring for a child with FASD" when studying mothers' experiences raising a child with FASD. Caregivers needed to parent children based on their unique strengths and challenges. Caregivers discussed strategies that they used and in each case, it was essential to modify their expectations.

Caregivers reported ways they kept their homes calm and predictable. This has been noted in the literature. Repetition, stability and routine helped children with FASD function in daily life (Child and Youth Working Group, 2007). Streissguth et al. (1988) also said that one essential environmental component to help a child with FASD be successful was structure, and Olson and Montague (2011) stated routine and stability were necessary to prevent over-stimulation.

Communication techniques were also mentioned in this concept, suggesting that when parenting children with FASD, changing communication style was important. There was evidence in the literature for this. For example, Lutke (1993) identified alcohol-affected children as being literal, and suggested using short sentences and precise

language (as cited in Streissguth, 1997). The Child and Youth Working Group (2007) suggested caregivers be direct and clear in their communication with alcohol affected children and youth.

Strategies caregivers reported they used for when a child was upset or had a tantrum included distracting and preventing rages before they became full blown, as well as walking away. Existing literature referenced the same strategies, such as learning triggers to try to avoid rages, and letting the tantrum run its course as long as the child is safe (Child and Youth Working Group, 2007).

**Use non-verbal, sensory, and physical strategies.** In this concept, caregivers noted non-verbal, sensory and physical strategies they found helpful in making their household function well. These strategies were noted in the literature as beneficial for children with FASD, but in the professional literature and when describing areas of concern. It is likely that the caregivers in the present study have noted these strategies working through trial and error, and also have interacted with professionals such as Occupational Therapy and Physiotherapy, who have recommended these approaches. These caregivers were connected in the community as well as had the motivation, capacity and means to ensure their alcohol-affected children received appropriate care.

Social cognitive process impairments have been found in children with prenatal exposure to alcohol (McGee et al., 2009), along with language and communication deficits (Coggins et al., 2007). Siklos (2008) also reported that children with FASD had trouble recognizing emotions, which attenuated social skills. This concept included responses to combat these difficulties such as exaggerating emotions, using visual cues, implementing sensory objects and non-verbal communication. Communicating through

eye contact, exaggerated paralinguistic behaviours and using visual cues have all been noted in the literature to help communicate with an FASD population (Child and Youth Working Group, 2007). Caregivers expressed the need to use these alternate forms of communication regularly with their children with FASD.

**Stay patient and understanding.** This concept represented personal needs of the caregivers to maintain a functioning household. Caregivers included both strategies, as well as important reminders and characteristics for themselves in this concept. This concept was consistent with the literature on caregiving children with FASD.

A protective factor for children with FASD was having a caregiver with the right personality and skills (Olson & Montague, 2011). Streissguth (1997) identified hope and a practical approach as important qualities for caregivers raising children with FASD. Caregivers in this study identified these characteristics in themselves, for example being optimistic and realistic, as well as making an effort to find things that work through trial and error.

Obtaining as much knowledge as possible was a response found in this concept that was a strength for maintaining a functioning household. Foster parents who did not know their child had FASD or was not FASD informed struggled trying to understand the behaviours they observed and did not know how to intervene (Brown et al., 2007). Reframing caregivers' understandings of the child's behaviour as a result of brain damage helped them form a more positive view of their child (Olson & Montague, 2011).

Hassall et al. (2005) noted that locus of control mediated parenting stress. Caregivers in the present study identified this as well, highlighting the need to accept the irreversibility of the disorder and know the behaviours are not intentional. Weiner and

Morse (1994) found that understanding the disorder helped assuage feelings of guilt, and Blacher and Baker (2007) found that in high stress parenting situations, the more positive the caregiver's views on parenting were, the lower were their stress levels.

Brown et al. (2005) found flexibility, loving, high endurance and dedication to be important caregiver characteristics in raising a child with FASD. Similar characteristics were noted in the responses of this concept. Caregivers identified other characteristics that were important for raising a child with FASD, including learning from their child, having high tolerance and understanding as well as being supportive and validating. These results are comparable to a study by Brown and Bednar (2003), who found that managing difficult children must be based on understanding, commitment and listening.

**Locate and maintain external supports.** This concept represented the benefit of having support when raising a child with FASD. This included personal and professional support as well as other external influences that helped the household function well. Many of the responses in this concept were consistent with results from previous studies, however some specific strategies mentioned were unique to the present study.

Bailey (2007) noted that families with supports do better overall. In a study by Brown et al. (2005) foster parents raising a child with FASD found it beneficial to have immediate family and neighbour support and caregivers in the present study also reported personal support as being a strength to make their household function well.

Responses in this concept highlighted the importance of group and professional support. Interactions with other caregivers were shown to relieve stress, provide guidance and allow sharing of information (Olson & Montague, 2011). Brown and Bednar (2003) noted that a strong health and social service team was a need. Furthermore, a

multidisciplinary team was needed to diagnose and treat those with FASD (Streissguth, 1997). Responses in this concept reflected the professional support needed, such as a good pediatrician and connecting with specialized professionals.

Respite care was an important need for caregivers raising high needs children, and this was identified as well. Parks and Novielli (2000) found that social support was essential in relieving caregiver stress, particularly in providing respite care. "Making time for themselves" was a concept Brown and Bednar (2004) noted in their study of caregivers of children with FASD.

Some unique responses in this concept include the use of traditional Aboriginal methods including spiritual strengths and traditional medicines. Traditional Aboriginal families raising a child with FASD have not been a target population in FASD research thus far. The strengths of Aboriginal families raising a child with FASD have yet to be explored in the literature.

Other strategies noted in this study were music and a service dog. These have not been identified in existing literature and have potential to be of consideration in future studies. The caregivers in this study are knowledgeable and open to exploratory methods for helping children with FASD. These caregivers are involved in the FASD community, know the disorder well, and therefore have a clearer understanding of possibilities for affected children and their families.

### **Discussion Summary**

In response to the question: "What challenges do you face making your household function well?" there were seven concepts including: 1) Extra Responsibility on Caregivers, 2) Difficulty Keeping Daily Routine, 3) Lacking Professional and Personal

Support, 4) Feeling Stigmatized and Isolated, 5) Working with Child's Diminished Executive Functioning, 6) Managing Child's Self-Regulation Problems and 7) Addressing Child's Antisocial Behaviour. Results of the present analysis were similar to findings in the existing literature. Caregivers in previous studies have expressed feeling an extra load of responsibility raising a child with FASD as well as the difficulties in finding personal and professional support. Feeling stigmatized and isolated were also previously noted, as well as the difficulties with raising a child with FASD in rural communities. Poor emotion control, immature behaviour and the struggle with the invisibility of the disorder were identified by caregivers within the results of previous studies. Antisocial behaviour including stealing, lying, and poor school attendance have also been reported in the literature.

However, this study also revealed some unique challenges that had not been noted by caregivers in previous research. In the concept daily routine, there has not been much research from the caregiver side. It is known that schedules help, however, caregivers expressing the hardship of keeping a daily routine is new to the literature. Homeschooling was also a new area in the area of FASD as there has not been much literature investigating homeschooling FASD children and the impact it has on caregivers. Finally the concept about executive functioning is new to the literature with caregivers as participants. Although there has been research done demonstrating the effect FASD has on executive functioning, this has yet to be expressed from caregivers as well as the struggles they have caring for someone with these difficulties.

One topic that was found in a thematic analysis of the literature but was not expressed by the caregivers in this study was transitioning to adulthood. Although this

study included children with FASD of any age, caregivers did not mention transitioning to adulthood as a challenge in making their household function well. In this study, the average age of the child with FASD was 12.1 years old. Most of the caregivers who participated were raising younger children, so transitioning to adulthood may not have been a concern for them at the time. In the literature, Olson et al. (2009) discussed parents raising a child with FASD needing to understand the possibility of being parents for life and planning for a long term future. Clark et al. (2008) recognized the lack of transitioning services for youth with FASD in British Columbia and although caregivers mentioned service needs, they did not specify for transitioning.

Responses to the question "What strengths do you have making your household function well?" resulted in four concepts including: 1) Change Parenting Strategy for Different Children, 2) Use Non-Verbal, Sensory and Physical Strategies, 3) Stay Patient and Understanding and 4) Locate and Maintain External Supports. Results of the present study were largely consistent with responses from caregivers in other studies. Caregivers have found that it important to understand the child as an individual and therefore use parenting strategies that are tailored for him/her. Specifically, non-verbal, sensory and physical strategies have been mentioned by both professionals and caregivers. Key positive characteristics of caregivers have also been found in the literature, such as being understanding and patient. The unequivocal need for supports and the help they provide is also consistent with responses from caregivers in previous studies.

Overall the strengths found in this study overlap with many mentioned in previous literature. However some new strategies caregivers found beneficial were to maintain good communication when child is upset, teach the same skills in different environments



to allow for transferring skills, listen to music, use Aboriginal cultural methods and get a service dog. The caregivers in this study were individuals connected to agencies, other caregivers and have received support. These caregivers were advocates and sophisticated in their knowledge of FASD. Furthermore, there is a lack of literature in strengths of families raising a child with FASD, so these strengths have not been explored before.

### **Implications**

The results of this study add to the existing literature on challenges and strengths caregivers raising a child with FASD face in their daily household functioning. While many challenges and strengths mentioned were similar to those found in previous literature, the unique strategies caregivers have found to work will aide many families looking for strategies and techniques to help their alcohol-affected child. These strategies also warrant further research and will broaden professional knowledge of FASD.

Recent research on FASD ranges from understanding the biology of fetal alcohol, to phenotypic presentations, to the family and community aspects of this disorder and there is still much to learn. Questions arise about the differences between types of caregivers, such as foster, adoptive, birth, and kinship, as well as the differences in diagnosis, between ARND to full blown FAS. The discrepancy in access to services and knowledge between rural and urban caregivers is another area of interest. Age of diagnosis is yet another area requiring further research, as infants who receive a FASD diagnosis are likely differently raised than those who receive a diagnosis at later ages. Further research in FASD could explore the effects of addressing some challenges caregivers outlined. For example, what changes are noted when a family with a child with FASD has access to respite, if foster parents foster longer or have better experiences

when FASD informed, and how FASD services in rural communities are received.

Further research in strengths caregivers have could focus on strategies caregivers have found to work, further explore the reason why these particular strategies are working and give merit to strategies found to work effectively. Due to the lack of understanding around FASD for both communities and professionals, it is important to address these questions to improve the lives of families raising a child with FASD. There are many gaps present in the literature in caregiving for children with FASD.

Research and practice need to capitalize on what parents of alcohol-affected children have learned about what works for them. Research in the area of family supports has been more frequently conducted in the United States. Although Canada and the United States are similar, key differences in the structure and ideology of communities and policies make it vital to understand Canadian families as a unique population. By learning more about the home life of a child with FASD, this information can be used across disciplines, informing medicine, nursing, education, public health, occupational therapy and several other fields. FASD is a condition that is relevant to numerous fields of study and all professionals can benefit from an understanding of how households with an affected member function. This will inform suggestions of techniques, strategies, and interventions to help them be more easily integrated into the family system, and adhere to the lives of the families involved.

Ultimately, the research aids in creating a good home environment for children with FASD. More knowledge about raising children with FASD will contribute to better parenting and fostering of these children, increasing the chance for affected children to move successfully into adulthood, and, in turn, helping to create a stronger community of

service and support for families affected by FASD.

### **Limitations**

There is always a bias in voluntary research selecting for people who demonstrate characteristics, lifestyle, knowledge, which make them willing to participate and those who do not. Another potential bias in the data is interviewing one caregiver over another within the same household. Different caregivers in the same family may have different views on what strengths exist and what challenges are faced in raising their child. For example, often males and females have different parenting styles (Stephens, 2009), and therefore the results may differ depending on the caregiver that is interviewed. Furthermore, this study is focused on families who have had connection with FASD support and services already. This population may differ significantly from all families affected by FASD, as these families are aware of the disorder, and have been in contact with some support services. The current study is also looking at experiences of caregivers in a particular geographic area in southern Ontario. The focus is on local families and the results may not generalize to caregivers for children with FASD in other communities. Location, caregiver, support services and willingness to participant in a study all make this sample unique.

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## Appendix: Interview Questions

ID# \_\_\_\_\_

Caregiver sex \_\_\_\_\_

Number of Children current/past with suspected or confirmed FASD

\_\_\_\_\_/\_\_\_\_\_

Relationship with Child(ren) suspected or confirmed FASD

\_\_\_\_\_

Years as primary caregiver to current \_\_\_\_\_

Other caregivers in home

\_\_\_\_\_

Average Yearly Family Income (less than \$50,000) (50,001-100,000) (100,001+)

Occupation \_\_\_\_\_

Total current # children in household

\_\_\_\_\_

Current children with FASD

Alcohol-Related Diagnosis received?	Yes	No
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On waitlist for Diagnostic service?	Yes (how long_____?)	No
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Other diagnoses received \_\_\_\_\_

Ages of child \_\_\_\_\_

Sexes of child \_\_\_\_\_

Grades of child \_\_\_\_\_

Ethnicities of child \_\_\_\_\_

Children Suspected of FASD Screening Form

*Child Behavior (of oldest current child aged \_\_\_\_\_ suspected of FASD, \*2\* years or older)*

1. Does the child act too young for his/her age?

Yes/No

2. Does the child have difficulty concentrating, and can't pay attention for long?

Yes/No

3. Is the child disobedient at home?

Yes/No

4. Does the child lie or cheat?

Yes/No

5. Does the child lack guilt after misbehaving?

Yes/No

6. Does the child act impulsively and without thinking?

Yes/No

7. Does the child have difficulty sitting still/is restless/hyperactive?

Yes/No

8. Does the child display acts of cruelty, bullying or meanness to others?

Yes/No

9. Does the child steal from home?

Yes/No

10. Does the child steal outside of home?

Yes/No

**Open-Ended Questions:**

- 1) What challenges do you face in making your household function well?
- 2) What strengths do you have to make your household function well?



## *Caregivers' Experiences Raising a Child with FASD*

### LETTER OF INFORMATION (Phase 1)\*\*

(\*\*will be read via telephone)

#### **Introduction**

My name is Aamena Kapasi and I am a graduate student at the Faculty of Education at Western University. I am conducting research into caregiver's experiences raising a child with FASD and would like to invite you to participate in this study.

#### **Purpose of the study**

The aims of this study are to explore the experience of raising a child with FASD in regards to household functioning, school related concerns, and transitioning into adulthood.

#### **If you agree to participate**

If you agree to participate in this study you will be asked to have a telephone interview at a convenient time, and answer some questions about this topic. The interview would take about an hour. I would like to audio-record our conversation, if that is ok with you.

At the end of the interview, I will ask you if you are interested in helping us group the results together after all of the interviews are finished. Direct quotes from Phase 1 will be used, but WILL NOT include identifying (i.e. names or locations) information. If you are interested, I will get your contact information and follow up with you in about 8 weeks.

#### **Confidentiality**

The information collected will be used for research purposes only, and neither your name nor information which could identify you will be used in any publication or presentation of the study results unless you give me explicit consent to identify you by name in the report. Otherwise, all information collected for the study will be kept confidential.

#### **Risks & Benefits**

There are no known risks to participating in this study.

#### **Voluntary Participation**

Participation in this study is voluntary. You will receive a gift certificate for your time. You may refuse to participate, refuse to answer any questions or withdraw from the study at any time with no effect on your status as a caregiver, and still receive the honorarium.

#### **Questions**

If you have any questions about the conduct of this study or your rights as a research participant you may contact Dr. Jason Brown at or the Office of Research Ethics, Western University.

[Signature]

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## Curriculum Vitae

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AAMENA KAPASI

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### Education

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#### **Master of Education in Counselling Psychology**

Anticipated Convocation: June 2015

*The University of Western Ontario, London, ON*

#### **Bachelor of Science with Specialization in Psychology**

June 2015

*The University of Alberta, Edmonton, AB*

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### Counselling Related Experience

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#### **Counsellor Intern**

Sept. 2014 – May 2015

*Thames Valley District School Board, London, ON*

#### **Psychology Intern**

May 2013-May 2014

*Turningpoint Program, Alberta Hospital Edmonton*

#### **Distress Line Listener**

Sept. 2011 – August 2013

*The Crisis Intervention and Suicide Prevention Centre of British Columbia, Vancouver, BC*

#### **Student Peer Supporter**

Sept. 2010 – April 2011

*Peer Support Centre at the University of Alberta, Edmonton, AB*

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### Research Related Experience

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#### **Research Assistant**

January 2014 – April 2015

*Department of Counselling Psychology, University of Western Ontario*

#### **Research Assistant**

September 2012 – August 2013

*Alberta Brain and Cognitive Development Laboratory*

#### **Research Assistant**

January 2010 – June 2012

*Neuropsychopharmacology Laboratory, University of Alberta*

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### Presentations and Publications

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#### Presentations

Kapasi, A. & Brown, J. (May 19-22 2015). Caregivers' Experience Raising a Child with Fetal Alcohol Spectrum Disorder. Poster presentation, Canadian Counselling and Psychotherapy Association, Niagara Falls, Canada.

Kapasi, A. & Brown, J.(March 4-8 2015). Caregivers' Experience Raising a Child with Fetal Alcohol Spectrum Disorder. Poster presentation, 6th International Conference on FASD: Research: Results and Relevance 2015, Vancouver, Canada.

Kapasi, A. (February 4, 2015). Fetal Alcohol Spectrum Disorder: Information for Elementary Teachers. *Course 5005 Educational Psychology and Special Education*. Lecture conducted from Western University, London, ON.

Kapasi, A. (February 6, 2015). Fetal Alcohol Spectrum Disorder: Information for Secondary Teachers. *Course 5005 Educational Psychology and Special Education*. Lecture conducted from Western University, London, ON.

### Publications

Brown, J., **Kapasi, A.**, Bird, R. (Accepted). *Caregivers of children who are prenatally exposed to alcohol*. Parenting: Behaviors, Cultural Influences and Impact on Childhood Health. New York: Nova.

Brown, J., & **Kapasi, A.** (2014). Manitoba Foster Family Network Peer Support Program Evaluation Report. Western University, London, Ontario.

Elke, S., **Kapasi, A.**, Shi, D., & Wiebe, S. A. (April 4 - 8, 2014). Gender differences in emotion regulation and attention in early and middle childhood. Poster presentation, Cognitive Neuroscience Society Annual Meeting, Boston, MA.

Elke, S., Shi, D., Khoei, M., **Kapasi, A.**, & Wiebe, S. (April, 2013). Neural correlates of response conflict and emotional regulation in middle childhood. Poster presented at Cognitive Neuroscience Society, San Francisco, California.